



2013 North American Education Program

Making Treatment & Lifestyle Decisions: Thinking About Benefits & Risks

THE HISTORY OF MS TREATMENT OPTIONS

Dr. Bar-Or: Until the early 1990s, MS could be categorized as yet another neurological condition that could be diagnosed but for which there was really little to offer patients in terms of changing the course of their illness.

Dr. Fox: And now in the last 20 years we have 10 FDA approved therapies to change the course of MS. So there's really been a dramatic change over the last two decades, from a completely untreatable disease, to now a disease that we can treat quite effectively. One of the downsides of having so many therapies now is choosing which one to use.

KNOWLEDGE DRIVES DECISION MAKING

Dr. Bar-Or: There has been a very exciting evolution of treatments in the world of multiple sclerosis, starting with the injectable immune modulators which as MS transitioned into a treatable condition, this was a very welcome addition.

Dr. Fox: Now in the last 10 years we have many new therapies. We have infusion therapies that are highly effective and given infrequently, we also have oral therapies that appear as best as we can tell to be more effective than the older injectable therapies.

Dr. Bar Or: On the other hand the newer treatments often come with different type of baggage, such as potentially increased risk or side effect profiles, tolerability issues may be different.

Dr. Fox: They are relatively new, so we don't know the longer term side effects, particularly of the newer oral therapies. But at least based on what we know to this point, it seems very encouraging in terms of the efficacy, the safety and the tolerability of these newer therapies.

DISEASE MODIFYING THERAPIES

Dr. Bar-Or: While there's been a tremendously exciting evolution of treatment opportunities or options for patients in the world of MS, we still don't really have a perfect treatment. A perfect treatment would be one that would be very easy to take, would be absolutely safe, would have no problems of tolerability, and would be 100% effective. That in essence would be a type of cure. We haven't reached that. We have treatments that are increasingly good at limiting the frequency of relapses. And part of that is because we have gotten better and better at understanding the biology that contributes to relapses in people who have MS. People often wonder if there are particular benefits

to starting treatment early. Intuitively of course if we can limit injury to the central nervous system that is better done early rather than late.

Dr. Fox: Early in MS, there's active inflammation that comes into the brain and the spinal cord and causes acute injury. It takes the myelin sheath off of the nerves, but it also cuts the nerves at that very early stage. Although patients typically recover quite well from their relapses, we do know from MRI studies that there is a lot of injury left. There's scarring and there's shrinkage of the brain or atrophy that is left after that acute inflammation. Once that injury has set up, once the axons have been cut and the sheath has been removed, it's very hard to rebuild that tissue and we actually don't know how to rebuild the axons, the nerve fibers that have been cut by the acute injury.

Dr. Bar-Or: We do know that injury to the central nervous system for people who experience or live with MS can happen both because of relapses that don't get completely better and also because of what has been called progressive MS, whether it's the secondary progressive MS that patients who initially have a relapsing remitting course might eventually experience, or the less commonly experienced primary progressive MS where people progress from the very onset without there being any evidence of relapses.

Dr. Fox: By starting early, we're preventing that injury. The time to treat is early on, right when the active inflammation is occurring.

MAKING DISEASE MODIFYING THERAPY DECISIONS

Alexander: From the first day of my diagnosis is when I first started thinking about my treatment options.

Patty: As soon as I got the diagnosis I wanted treatment that day.

Alexander: I just wanted to I guess give myself the best chance I had to kind of preserve my function for my functional abilities as long as I possibly could.

Jennifer: I immediately began researching the drugs that were available and I started researching not just how those drugs worked and, and how you took them, but what their side effects were

Aaron: It was difficult um, because I was getting information from all sides, and you had to process all of it. And so that made my doctor that much more important, uh it was somebody that I trusted, uh and it was something that helped me wade through all that information

Jennifer: My doctor was great about actually outlining for me the different types of treatment there are involved in any kind of chronic illness. With Multiple Sclerosis there is the disease modifying drugs. The things that help slow down the progression of your disease. But then there is that second side of things where, how do you manage your symptoms? What are the things that you do both medically and physically to help put you in the best position to manage your disease overall?

Patty: Back in July when I was coming off of a therapy for risk factors, I was on no disease modifying therapy until December. That time in my life um, I did have a relapse and my relapse was bad, so we discussed options and an option was an oral medication. It did not work for me, so that oral medication was stopped on day 2 and I was started back on infusion therapy because the risk of PML was less of a risk than being off therapy to me.

Dr. Bar-Or: One of the things that people often don't introduce is the risk of not making a treatment choice.

Dr. Fox: Sometimes in reviewing the risks of therapies with patients that they get very focused on the potential risk and they lose track of the purpose of the medicine and, and the purpose of the medicine is to prevent relapses, prevent progressive disability, prevent scars and injury to the brain and the spinal cord and they get very focused on well, I don't want to have diarrhea, I don't want to have flu like side effects. I don't want to have skin reactions. I, and they, they will sometimes lose track of the bigger picture of what we're trying to do to prevent this disease from causing progressive disability.

Dr. Bar-Or: There are people and particularly those for whom their MS experience has not been particularly difficult, they may feel why do something that might make me feel bad or put me at risk if I'm not really having problems with my MS. In this regard it's very important to help them understand that in MS we now know

there can be activity under the surface that can contribute to injury and that this injury may be very important over time so that a person who may not have any obviously relapses might nonetheless take multiple hits to their central nervous system in a way that today at least we don't know how to fix.

Aaron: I started one disease modifying drug in, in July of 2003. Um, and then about four years later uh, I did have a lesion show up on my uh, MRI so the doctor and I had a discussion and he said, look, we don't know if your disease has been dormant, um, and the drug is doing nothing, or that, that the drug has held all the other lesions at bay. Um, but he said let's err on the side of caution and switch medications

Patty: Since my initial diagnosis 10 years ago I've been on injectables, infusion, oral medication, all of which worked extremely well for me but because of side effects that required me to come off, I had to keep seeking a different therapy

Alexander: The first therapy that I tried was the interferon and I was on it for about 6 months but I think uh we knew pretty quickly, me and my neurologist knew pretty quickly that it was not uh, not really ideal for me just because I kept on having the relapses. I was faced with the option to you know go to a sort of second line therapy or I could get you know as aggressive as possible which is what I was more leaning towards. You know I wanted to really try to get the disease under control so I went with the uh, the most aggressive form of therapy that was available to me at the time.

Hana: We started by trying the simpler type, which was an everyday injection. But I, I took it for about a month or two, but I hated it because it was every day and I hate needles, then we started, we changed a medication to an every week type of an injection and, the first time I took the full dose of that medication, my body was shaking, big headache and fever and...we're going to try the pill and see if it works or not.

THE TREATMENT DECISION MATRIX

Deborah: There are a number of different factors that people need to take into consideration when they're choosing a medication.

Dr. Fox: We do know that the MS therapies have differences in their efficacy from one to another. We also know that the risk of complications from individual therapies can vary from one patient to another and can vary in terms of what we are willing to tolerate based on how active the disease is. And thirdly, we also know that different patients will have different side effects from any individual therapy.

Deborah: At this point I think that most people are willing and most interested in taking pills. That would seem natural. That's what most people do when they take medicine and for many that works just fine. But other people don't want the reminder every day of the fact that they have a condition for which they need to take medicine. And for them, some of the injectables that have fewer um, doses per week can be a much better and in some cases for people who have particularly active disease, it's good to know that they are being able to have multiple choices and can

escalate their treatments as they need to. In the case of the once a month infusion, for some people that's absolutely perfect because it's only one time a month and it's not part of their daily routine and it's outside of their household, so it's not interfering with their lifestyle. It's really great that people have options and it's very important for them to be aware of what their priorities are and what is going to lead to the greatest adherence.

Dr. Bar-Or: One could start with a treatment that is viewed as the most appropriate choice right now. I make the point that this is not a lifelong marriage to this particular treatment. If people understand that the first choice is made as the most sensible choice at that time, then there's the opportunity to see how they do. Will this treatment work enough to limit their MS new activity and will they as individuals tolerate this treatment, perhaps better than the average. If either of the answers to these questions are no, one can then engage in a new treatment choice.

Jennifer: The decision making process for me in choosing a disease modifying therapy was very, very inclusive but at the same time very fast

Aaron: Involved in that decision was not only myself and my wife, um, my mother, certainly my doctor because he had all the information and I wanted that information.

Alexandre: Everyone's there for support which is great, but at the same time you really have to make sure that you're uh, personally accountable ...and you know family, friends, maybe they're a little more risk averse sometimes so it's, you want to make sure that uh, that you're kind of making the decision for yourself and that was important for me.

Aaron: The first thing I did is I looked at all, as much information as I could. My wife and I knew we wanted children. So I wanted to stack the, the deck in my favor. Um, so anything that I could do so that I could chase my kids across my backyard I was going to do.

THE LEARNING CURVE

Deborah: There certainly is information overload in the MS world and the rest of the world today. We have very informed patients. Um, who for the most part are able to distinguish between what's good information and what may be less reliable information. They really know to be sure the source of the information and to check things like when was the last post made? Um, was it 10 years ago or was it yesterday?

Dr. Fox: in a disease that doesn't have a cure, which is MS, there is a lot of stories and, and there's a lot of desire to, to find that cure, to find that hidden answer to, to, to treat their MS.

Deborah: I had a patient come in um, who had brought with her a news story of a woman who changed her diet. And she went from being um, dependent on a wheelchair to walking independently.

And this patient actually wanted to know why we were withholding this treatment. And what we were able to talk through in the course of that session was that this is one person's experience, we know that MS is an exacerbating remitting disease, and that any time the course of the disease can change for better or for worse. And that while stories like someone who used to need a wheelchair and now can walk is very inspirational. It's not scientific proof.

Dr. Bar-Or: What has worked for one is an anecdote, is not necessarily something that will be broadly applicable across the board.

Deborah: A colleague of mine likes to say that the plural of anecdote is not evidence. So part of what we need to do is to help educate um, our patients, the people who come to us for care about being confident in their own decision making, helping them build skills to make decisions and to sort through the information

Jennifer: When you're researching disease modifying therapies, it's very important to know and trust and believe in your sources. ... What is the occurrence for someone that lives three states away with completely different climate and temperature that has completely different symptoms and reactions to things than you do, is not nearly as helpful and that's the kind of information that you may run across when you're researching therapies. In the end, I would really encourage anyone to come back to do you trust this source or not? And, and take that into consideration when you're making your choice.

Marie: We often direct people to the National MS Society website because we tell them that that's a solid source of information. It's in patient friendly terms, if they wanted to delve more into the information, there's also resources that they can look into beyond that. And that is really more of a, balanced look at you know the treatments that are available for them.

RISKY BUSINESS

Bar-Or: Looking back, the injectables, which carry a certain burden, both of the injections and potentially side effects and really only limit MS disease activity partially are now being viewed as very well understood treatments, ones that have a very clearly defined safety profile. Ones for which we expect no surprises and so one is very reassured about discussing these from a safety standpoint.

Dr. Fox: With the excitement of the new therapies for MS, there are three important caveats about them. One is that we don't know the long-term risks, so two year clinical trials only know the safety over two years and it's only with the longer-term experience that we know what the longer-term risks are. Secondly, the patients that go into clinical trials are generally very healthy and we don't have patients with various other medical complications that go into those trials. However, those patients are in our practices and we don't know necessarily how those therapies will interact with some of those more complicated patients. What we also don't know is the very rare risks. So when there's been a couple thousand patients studied for a couple years, we do know the risks that are at the level of one in 500, one in 1000. But we don't

know the one in 10,000 risks. The one in 20,000 risks until we get 20, 40, 60,000 patients on the therapy and followed for a period of time.

Deborah: As we talk to people about what their experience is likely to be on a drug, it's really important for us to emphasize that the patients should not be thinking in terms of the statistics that are associated with a clinical trial.

Marie: The information that we glean from clinical trials gives us an aggregate information. And it's a compilation of all the experience of those people who have been in a study. When we're talking with patients, it's a one on one. And we never really know how medication will work, um, if it's going to be effective and what the side effects are going to be for that particular individual.

Dr. Bar-Or: One of the most important nuances that comes to play in the context of treatment decisions has to do with risk aversion or risk tolerability that each person may have or that their family members or friends, loved ones might also bring to the table.

Marie: The patient may have one idea of the risk benefit ratio but the family member may have an entirely different idea. And certainly we know families and friends can influence a patient's decision.

Dr. Bar-Or: Turns out that people have a very broad range of what they might consider acceptable risk or unacceptable risk.

Dr. Fox: There was a survey done with the NARCOMS MS Patient Registry where 5,000 MS patients were asked a hypothetical question about a hypothetical MS therapy and what risks they were willing to tolerate for that therapy. And there were some patients who wouldn't tolerate any risk for that hypothetical MS therapy and there were others that would tolerate a risk of, of up to 50% risk of death or higher for that potential, again hypothetical therapy.

Dr. Bar-Or: If a person is doing very well with their MS overall, and we're suggesting a treatment that might limit relapses, so it's kind of an investment in the future because they are very, very functional, they may be willing to take much less risk to decrease new injury because they have had a pretty good experience overall with their MS. On the other hand the person who's experienced relapses that have not gotten better and have left them with some degree of dysfunction might be much more motivated and much less concerned about the risk that might be associated with a treatment because they understand personally that limiting new relapses may be very important for them.

Dr. Fox: It's important to remind patients that being aggressive or conservative is not right or wrong. It's just a style.

Jennifer: For me it was important to consider the risk of doing something versus not doing something, and I believe the risk of not doing something was way greater than the risk of doing

something which is why I went on therapy so quickly and I'm grateful for that decision.

Hana: I know that every pill has or every injection has secondary effect but how, how bad is it going to react on me? And it reacts on different people different ways.

Aaron: Risk played a, played a part in my decision because when you compare and contrast those medications and they list out all of the possible side effects, I opted for the one that had the least uh the least dramatic side effects if you will, because I needed to be around. I needed to be around as a wage earner for my family, for, as a husband to my, to my wife and as a dad to my kids.

Jennifer: Risks, when it comes to multiple sclerosis, really aren't that different from any other risks that you're considering. It's your health and it's really, really, really important and at the same time you still have to think about what your long-term goals are.

Alexander: When I was first diagnosed, um, you know I had a little bit of numbness, but everything else you know I was really able to sort of do everything I wanted to do and I didn't really have to think about it. So it was a lot more, a lot easier to kind of go with the traditional route and not really ask as many questions. As I was faced with a bit more you know permanent disabilities in terms of you know my walking, my running, my energy level and things kept on getting worse and worse, that's kind of when I was sort of for--, forced to I guess consider the more risky types of treatment.

SWITCHING MEDICATIONS

Dr. Fox: Most clinicians do recommend patients who are stable and tolerating their current therapy to stay on that therapy.

Dr. Bar-Or: A person might decide to switch because their MS has not been sufficiently well controlled, or because they're having difficulties either with safety and tolerability. The decision to switch and what to switch to involves considering the particular medications in question. Sometimes we need to have a washout, a certain medicine needs to be stopped for a period of time so it's in essence out of the system prior to introducing the next treatment and this is a consideration that relates to the potential risks of the body being exposed to two different treatments at the same time that which might cause problems that any one treatment alone would not result in. Another consideration that has come up in the context of switches, or coming off a particular therapy is the concern that certain treatments when discontinued might be associated with a rebound or with increased MS activity.

Dr. Fox: And that is if we had too much of a washout the disease comes back. and some patients it comes back with a vengeance. It is very active with many, many lesions, disabling relapses and that has to be balanced with the theoretical risks of the overlap and, and the potential complications of the overlap. So I think in the last couple years the trend has been to have less and less of a washout and to have much closer connection between the old therapy and the new therapy, so that we don't allow the disease

to come back. And it's really because the theoretical risk of overlapping two therapies is probably much, much lower than the real risk of the disease activity coming back and patients being left with a lot of injury and disability.

TREATMENT GOALS

Dr. Fox: Oftentimes patients and clinicians come at treating MS from somewhat different perspectives. I look at it from a relapse and lesions on the MRI. They look at it from a can I do what I want to do in life? Can I go to the soccer game? Can I go to work? Can I do what I want to do at home? They look at it from a functional point of view and I look at it from a lesion on the MRI point of view. Which view is right? They're both right. They both are just different facets of the same disease. And it's important to clarify with MS patients what is the goal of that second facet, that disease modifying therapy? It's not restorative. They're not going to feel better. It's not something that they are going to notice

Marie: I think patients want to feel better. Um, certainly patients are very concerned about relapses too and many patients these days are concerned about MRI activity. But I think there's just a little bit of disconnect between what the patients want to feel like and what the clinicians are looking for in terms of efficacy of treatment.

PROGRESS ON PROGRESSIVE MS

Dr. Fox: In contrast to the excitement over the many treatment options we have for relapsing forms of MS, we don't have any effective

therapies to alter the course of progressive MS. This includes primary progressive, and secondary progressive MS. One of the main challenges for developing a therapy for progressive MS is that we don't really understand what is progressive MS. We don't really know what's going on within the brain and the spinal cord that is causing that gradual, little by little progression of MS. We do know that it's probably not the same thing that is going on in the early stages. There is not active inflammation in the way we see it in early stages of MS. The anti-inflammatory therapies of early MS don't seem to work at all in progressive MS. So all of that points us towards the conclusion that whatever is going on is very different.

Dr. Bar-Or: Understanding the biology that contributes to injury is what will end up leading to the treatments that in the long run are going to be most effective to change the course of MS. And we now appreciate something that we hadn't appreciated for many years, that in MS there are two different biologies that can contribute to injury. We now understand that probably 20 to 30% of people who have primary progressive MS may actually have under the surface some of the relapsing biology. Now that's very interesting because while they have this biology under the surface, we do not actually appreciate that they have relapses clinically, and yet, treatments that have been effective in limiting relapses may still help limit injury, at least to some extent in these patients and can then change the worsening of neurological dysfunction which may be related to relapses. That said we still

have to understand what really underlies the progression of MS that is not related to relapses because that really is a different biology and requires a different category of treatments. One of the issues is that for relapsing remitting MS designing studies that are able to measure relapses and therefore ask whether a treatment is going to decrease the frequency or the severity of relapses, is relatively easy. On the other hand in people who do not have these relapses and we're trying to target progressive MS such as individuals with primary progressive MS, we don't have these relapses to count. Primary progressive MS studies that would actually have a chance of capturing changes in the trajectory of progression would be very, very large and part of the problem has to do with our ability to measure the outcome. One of the goals of the research community working together with the clinicians and the clinical trialists is to try to improve on what we call outcome measures. What is it that we actually measure in the context of the clinical trial that can tell us whether our medication is effective or not. And we need to do better in terms of outcome measures so that we can go beyond measuring disability over time which will take us again a long period with large numbers of patients to assess, but be able to get additional measures probably through some of the new MRI techniques or magnetic resonance imaging techniques that will allow us to understand under the surface and capture more quickly the benefit of a treatment on progression.

Dr. Fox: We don't have a therapy that alters the ultimate course of progressive MS, but we do have a lot of therapies that can improve the symptoms, improve the function of patients with progressive MS. We can help with weakness, we can help with spasticity, with walking, bladder, bowel, sexual, pain, there's so many different things, mood as well.

Marie: We have other rehabilitation therapies that could help with symptoms and so we need to talk to our patients about those options too.

OTHER WAYS YOU CAN MAKE A DIFFERENCE

Jennifer: Some of the things that I do to help make life manageable with multiple sclerosis is be much more aware of my body. I focus on stretching and doing things to make my body feel better. I've listened to my body when it tells me that I am tired or not feeling good and I get the rest.

Aaron: I drink an enormous amount of water on a daily basis. Um, I, I do it for my running but I also do it for my health because I, I know there are benefits to the hydration.

Hana : When I first moved into this place it, the kitchen was already designed like the holes under the sink and stuff like that. But I think when my MS grew a little bit on me, 3, 4 years ago, we redid it. So I can have a bit more stuff where I need it. I did a pantry in there and so it's easier for me to move around in the kitchen and cook and not banging

into stuff. and my bathroom is a roll in shower, so I took out the bathtub and shower is pretty big and amazing. It's really beautiful.

Patty: I do high fiber diet, low salt, um, I try to stay active.

Alexandre: I do a lot of swimming which is uh, more tolerable, you know a lot of cardiovascular activity at the gym like either on the rowing machine or on the bike and a lot of weights. I'm still able to be physically active, it's just a question of adapting the activity that I'm able to do. And for me, I think that you know just in terms of my general energy level, and uh, you know my day to day life, I think that physical activity has been sort of the most important thing that I've been able to really take control of.

SYMPTOM MANAGEMENT

Marie: In treating MS completely we need to do two things. We need to treat the MS, treat the disease and we need to treat symptoms. Symptom management is still the hallmark of care for people because symptoms are what really affects quality of life over time.

Hana: I went to a rehab center and they measured me to make a chair that's to my needs and easier for me, so the chair is pretty light for my arms cause fatigue level, I don't want to get tired just wheeling myself around.

Patty: Once I noticed my spasticity increasing before um, calling the doctor to up my medication I did call and we did some physical therapy.

Dr. Fox: If a patient has a certain symptom and I say try this medicine and they come in in a month and they say, well Doc, is it working? I say no, that's something you tell me. Is that symptom better? So I usually tell them if the disease modifying therapy is working, they tell me if the symptom therapy is working.

Deborah: Another important symptom that we can't ignore is depression. If a person is depressed it's really important to reach out to their healthcare provider because we can treat this condition and we can treat it very effectively.

LIFESTYLE STRATEGIES

Deborah: If you're a person with multiple sclerosis it's very important to keep in mind that that's not the only health concern you have. It's very important to have a primary care physician who can make sure that you have an annual general, general physical exam who is screening for conditions that cause cancer, that can cause heart disease, um, that can cause other conditions that can be life threatening. You need to take care of your general health as well as your multiple sclerosis.

Dr. Fox: To me, wellness refers to a number of different facets of a patient's health. It refers to their general health, it refers to their emotional health, it refers to nutrition and exercise and it's all those general things that we can do that impact not just our MS but all facets of our general health.

NUTRITION

Dr. Fox: Nutrition questions with MS are a bit tricky for us to answer.

Mostly because it's a very hard thing for us to study, it's a very hard thing to randomize patients to a healthy or an unhealthy diet and to see how their disease course goes over time. In general I recommend a healthy diet, low animal fat, high fruit and fiber. The high fiber can be helpful with constipation which is very common in MS patients. Also we've come to find in the last couple years that cardiovascular risks have an impact on progression of MS. And heart disease and stroke and hypertension and diabetes, these things do have a relationship to progression of MS.

Dr. Bar-Or : In some ways what makes it easy in terms of discussion habitual activities including nutrition and exercise in MS is that it seems that what's good for the heart is good for MS.

Dr. Fox: Very recent research has raised the question of salt relationship with MS and active inflammation. These studies were in a basic science laboratory using an animal model with MS and suggesting that there was a relationship between salt and inflammation in this animal model. Now there's a lot more work to be done to understand how salt may be related to MS activity in people, in humans

VITAMIN D

Bar-Or: Vitamin D is a vitamin that we now appreciate plays some role in the context of MS at the very least in terms of the risk of developing MS and research that is coming out more recently increasingly is pointing to vitamin D being relevant also for people who have established MS and may be relevant to the degree of MS activity they have.

Dr. Fox: There is increasing evidence that vitamin D deficiency is a risk factor for both getting MS and MS progression over time. It's important to recognize that it's only a modest risk factor and it's not the whole cause of MS. It's also important to recognize that it's vitamin D deficiency, it's only very, very low levels of vitamin D that appear to be a risk factor. Vitamin D in the normal to the high range is all the same and it doesn't seem that the mega vitamin D is preventive for MS, both getting MS and progression of MS. Although more studies are underway now and we look forward to learning more about vitamin D in the future.

EXERCISE

Marie: Years ago when individuals were diagnosed with multiple sclerosis I think the mantra was go home and rest. And patients were pretty much told to avoid exercise.

Dr. Bar-Or: The reason people have said that is because when people exercise or when they're exposed to increased temperatures for instance for any reason, they might temporarily have a worsening of their MS symptoms. That in fact is not reflecting new injury and is something that will come back to that person's baseline

once they've stopped engaging in the activity. It's going to get better once you stop the exercise, and since exercise is generally deemed to be good, both for MS and for a number of other good reasons, people should not be afraid of this kind of temporary worsening of their symptoms.

Marie: When we talk to a number of our patients about exercise they're, they report that they're fatigued and they're too tired to exercise, and we need to talk with them about the importance of exercise in helping actually improve fatigue.

Dr Fox: Now some patients will say well I can't exercise. I walk with a cane or a walker, or I'm in a wheelchair. No, you can still exercise. You can still exercise to the ability that you can exercise.

Deborah: Exercising doesn't necessarily mean breaking a sweat. It can mean meditation, it can be tai chi, it could be stretching.

Marie: They may need to see a physical therapist to develop the right exercise program for them or to develop an exercise program that they'll stick with and uh we strongly encourage exercise for all of our patients.

SMOKING

Marie: Now there's more and more information that smoking is hazardous to people who have multiple sclerosis in terms of disease

progression and increasing in symptoms. So we need to have this frank discussion with our patients. Another reason not to smoke is because of multiple sclerosis. In addition to the risks with heart disease, stroke and cancer, MS can also be included in that list.

Dr Bar Or: Smoke exposure including second hand smoke exposure may play a role in increasing the risk of developing multiple sclerosis and more recently studies are trying to look at whether people who living with MS smoke or do not smoke, whether this impacts the degree of MS activity and the degree of injury over time.

UNDERSTANDING COMPLEMENTARY AND ALTERNATIVE MEDICINE

Dr. Bar-Or: The agencies charged with making decisions about whether a treatment will come out to the market or not, such as the FDA in the US, the Health Protection Branch in Canada, or the EEMA in Europe are charged with trying to put together information that is collected in a very organized and structured way that will allow them to make the assessment between the balance between efficacy on one hand and safety on the other hand.

Deborah: The randomized trial um, for disease modifying therapies is the gold standard. Um, it's what we all expect of the FDA before a drug can be approved.

Dr. Fox: One of the challenges with complementary or alternative medicines, those that haven't gone through a rigorous clinical

trials and haven't gone through FDA review is we often don't know the efficacy and, and don't know much about the risks as well.

Marie: With a disease that we don't have a cause and we don't have a cure, patients want to try some other options and they want to feel empowered and I think with complementary and alternative therapy they feel that they can make a choice about this. But we don't know the risks or the benefits really of these therapies because most of them have really not been well researched or studies.

Dr Fox: Sometimes patients will say well it's all natural. so it, it needs to be balanced. Just because it's all natural doesn't mean it's safe and doesn't mean it will be helpful for your condition.

Deborah: It's very important to keep in mind as you're making decisions about taking prescription drugs versus over the counter supplements that the drugs that are prescribed by your physician have been approved by the FDA after very careful study. In terms of some of the complementary or alternative or wellness approaches that you take, it's very helpful for your doctor to know about those as well because some of them may influence the way that your disease modifying therapies or other prescriptions affect you. As physicians work with people with MS over time they really do come to appreciate what works and what doesn't, what can be beneficial and what can be harmful. So it's very important to use your healthcare professionals' accumulated

experience in making these choices with you who are trying to make them on your own.

MAKING COMFORTABLE DECISIONS

Deborah: Life is getting more and more complicated for people living with MS. They're facing very complex decisions. And it's really tough when they feel like they're alone either as an individual or as a family for making these choices. It's very important for them to know who is on their team, for helping to make these decisions. There's no one right or wrong decision, um, but it really is important for people to be comfortable with the decision that they've made

Jennifer: You have a long life ahead of you and I think your job as a patient of any disease is to figure out what's going to help you to live your life the best that you can the way you want to, to live it. And we're lucky enough that there's a lot of different options out there to support you in, in your future.