

# IT'S NOT AS SIMPLE AS PML...

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## BACKGROUND

- Previously a large percentage of the treatment anxiety we have dealt with as Multiple Sclerosis (MS) Specialist Nurses has been injection /needle phobias.
- Over the last 6 years in particular, we have had more treatment options made available for patients. With these more effective options has come increased risk for our patients and consequently increased anxiety when deciding which treatment they should choose.
- One of these risks is Progressive Multifocal Leukoencephalopathy (PML) which is a viral disorder which can have very serious consequences, possibly even death for someone who is immunocompromised.
- This is a case study of an MS patient who had anxiety about starting Natalizumab and some of the strategies we used to help her and to support her decision making.

## THE CASE

- 31 year old Female patient.
- Diagnosed with Multiple Sclerosis (MS) in 2009 at age 28, first episode of neurological dysfunction was in 2007.
- First came to Monash Health MS clinic in February 2010.
- Was from a regional area but living alone in a Melbourne suburb. Single with no family living close by.
- Worked for a supermarket chain in various roles.
- About a year after being diagnosed she moved back to where her family were, obtained a transfer with work and now has a position in the office at the local store.

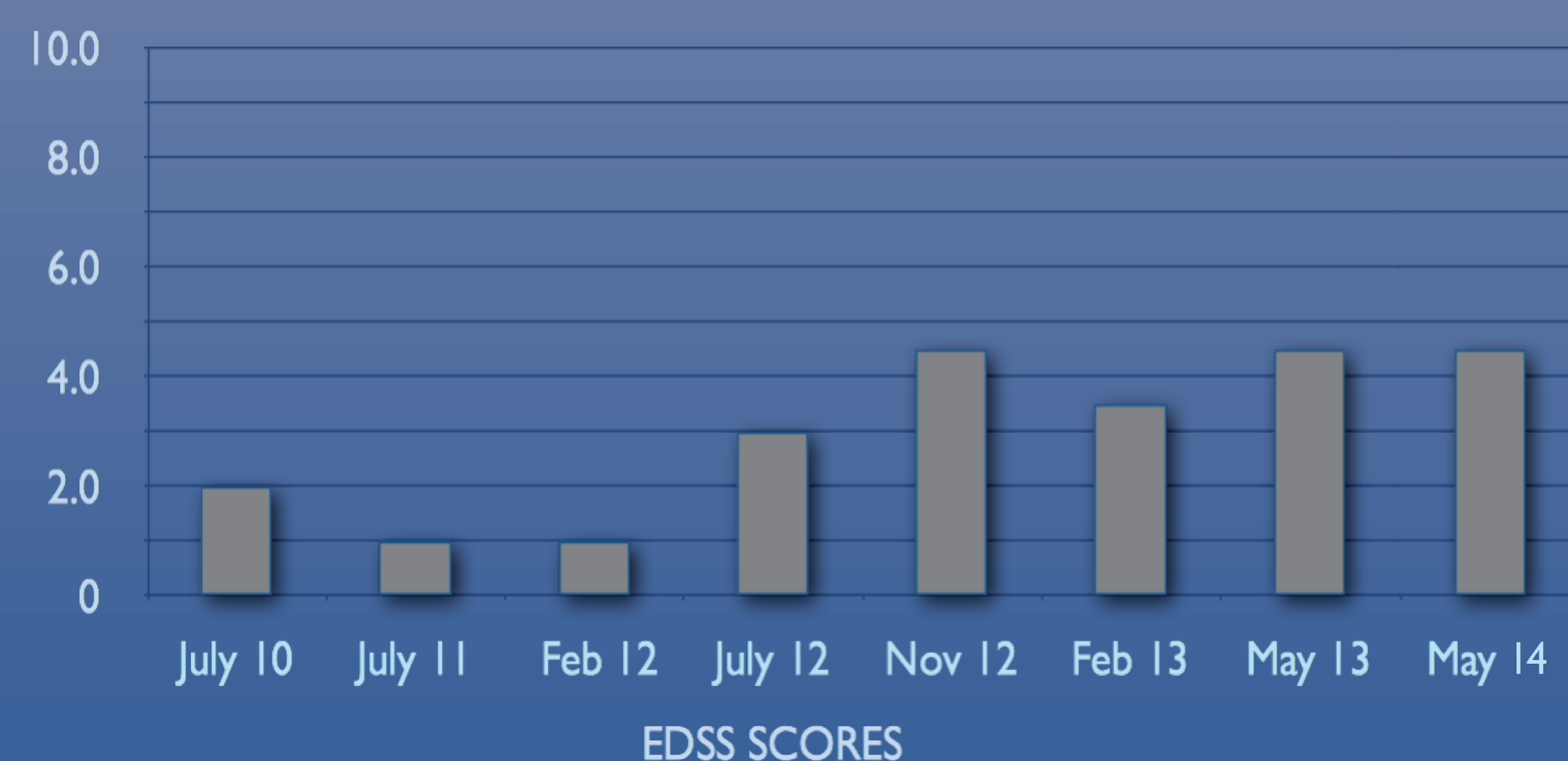


Figure 1.

## THE CHALLENGES

- 2010 - 3 relapses, December MRI showed 5 new brain lesions and new spinal lesions also.
- First 2 injectable treatment's (Glatiramer Acetate and IFN 1b s/c) not effectively controlling disease activity.
- 2011(Jan)- First mention of escalating treatment- options available at the time were Natalizumab(Tysabri) and Cladribine. Given information and education on both options.
- Chose to commence Cladribine.
- Did very well. Was walking with crutches before commencing Cladribine, 5 months later was running short distances. (Some of this was recovery from a relapse but importantly there was no new clinical activity).
- June 2011- Cladribine was taken off the market due to it's failure to get approval by the FDA. Our patient was understandably very upset with this decision.
- 2012 -Chose to go on Fingolimod once Cladribine course was complete. Said she didn't want to go on Tysabri ever.
- Did well initially on Fingolimod but within 15 months had 2 relapses.
- EDSS had gone from 1 to 4.5 since commencing Fingolimod in Feb 2012 ( Figure 1.)
- Was JCV negative - still resistant to Tysabri - Risk of PML was low at 0.1/1000.

**How do/did we help her make an informed and educated decision to go on a treatment that is the most effective available , that she has such a high level of anxiety about?**

## WHAT WORKED?

- Frequent email and phone contact- A good relationship.
- I asked her to put down in an email what her concerns were about Tysabri- it wasn't as simple as PML. It allowed both of us to have something concrete to work with. There were questions and concerns I could answer, that she hadn't been able to articulate before. (Figure 3.)
- I listened to her concerns- she didn't want to hear that she was being silly or that everyone was doing great on Tysabri. She just wanted someone to listen to what she was worried about.
- Ubersense- an iPhone application that allows us to compare videos taken of our patients walking. We had one video from the beginning of this year and one in June for this particular patient. Seeing them next to each other really helped her to see the difference that there was in her walking over 6 months, and to make a decision regarding her treatment. (Figure 2.) It was quite impressive seeing the difference!

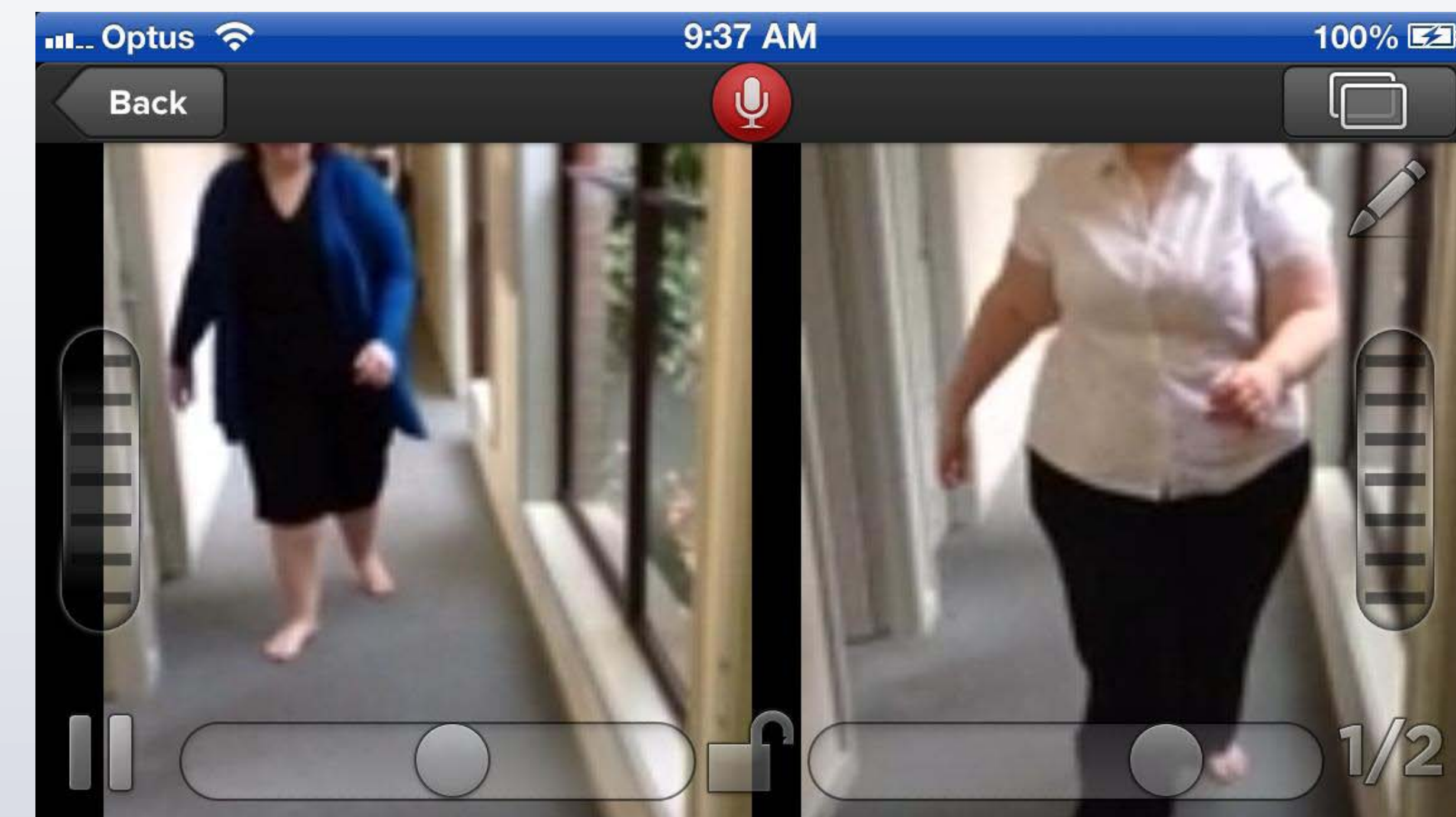


Figure 2. Ubersense video comparing our patient walking.

Hi there, so where do i start ? Obviously PML is my biggest thing, Then reading the symptoms for PML, how would I know i was getting PML and not just another attack? I have attacks so often that i don't bother doing anything or saying anything until it's pretty obvious. Then there was that card they give you to have on you at all times None of my MS medications have ever needed a card. It frightens the hell out of me. Then there is needing to go to hospital every month.. what if i want to go on holidays? Plus needing to take time off work every month.

Then I hear of people saying how tired, drained they are, and are hanging out for their next infusion which is a few days or a week away. Sounds like a junkie!

Figure 3. Excerpts from email

## THE OUTCOME

- Our patient started Tysabri in July 2013.
- She still had a lot of anxiety about starting it but could see that it was the best decision for her care.
- To help reduce her anxiety about starting Tysabri, and as some extra support, I was able to organise to fly up and be with the patient at the regional centre when she had her first treatment.
- It went well, she was glad to have a familiar face with her during her first infusion.
- Our patient has now been on Tysabri for 11 months. Her disease has been stable during this time. Her latest MRI (May 2014) showed no contrast enhancing lesions and no change from the previous one from 12 months ago. Her EDSS has remained stable at 4.5.
- She has been able to walk longer distances (Just completed 5 km fundraising walk for MS) without assistance. Hopefully we will still see some small improvements in EDSS but overall stable disease on Tysabri, and less anxiety around being on tysabri. A good result!