

All the comments provided in answer to the question "Is there any other type of support you would like to see MS Australia provide for people who are considering or trying an oral MS treatment?"

24 hour support should be made available. MS keeps odd hours.

A simple overview of what treatments are available or going to be available so that there is time to evaluate and discern about future options

a support group where people with ms on oral medications could talk about their experience.

Ability to combine this medication with treatment of veins that drain the CNS. Maybe some unbiased information about CCSVI would also be appreciated. It's hard to distinguish this survey from MS Society and drug company.

Adequate G.P support. A knowledgeable well informed doctor who can support you through all aspects of taking the medication

advocate for it to be financially available

All information should be available to us, whether it be good, bad or ugly so that we can make well informed decisions. All possible side effects also need to be noted and the frequency of those. The number of actual people taking the oral drugs and also continued comparative studies on effectiveness amongst oral drugs, and/or compared to other forms of treatment as there is NOT enough 'true' information supplied. We're sick of being public guinea pigs as in take this and not be told the side effects even when asked. It should be up to the patient to decide if they want to trial or take this medication based on truthful facts, not by the means of kickbacks to GP's, neurologists for prescribing it and we all know that is the truth.

All of the above

an information session for ms people to attend, to listen to info and to ask questions

assisting with research into short and long term results of this treatment

Better education for GP's on all aspects of this Disease and the medications available both orally and injectable

Community nurses well briefed to deal with local questions

Continue pushing the government to have it listed on the pbs

Contrast alternatives, including non-pharmacological approaches. Focus on side effects, some are worse than MS itself.

evidence of effectiveness ahead of changes to injectable medication that seems to work in modifying MS

Explanation of how the oral treatment modifies the disease.

Face to Face Information Sessions held regionally

feedback from the patient on the effectiveness of the drug

forum on the web where ordinary people can provide their experiences when using the drugs - possibly with questions. Answers provided by professionals - could also be comments on experiences.

Full disclosure of potential adverse side effects. No glossy magazines skating over the issues.

fund extended consults with neurologist & local MS nurse who will support you in your local area. Not Blackburn on the net etc!

George Jelinek runs an excellent session on the different meds on his retreats - something like that is

useful where it is unhurried, reliable info and questions can be asked

Honesty of any/all known side effects (real) people have had.

I am not sure; I would first need the whole-hearted support of my neurologist suggesting that the oral medication would be effective and suitable for me before I would think of any other support that I might need.

I am starting the oral medication soon and I am getting support from the specialist nurse at the neurologists, support from MS society nurses would also be of good value.

I DON'T KNOW

I generally choose my treatment based on my neurologist suggestions and further research

I have rang MS Society about this matter, expressed my concerns, regarding side effects on the blood. was not entirely satisfied with the response i received. it seems what ever is available, what the hell just take it you have no other joice. THERE IS ALWAYS A JOICE.

I know MS Australia provide fantastic support. I would really expect the support and knowledge to come from my Nuero and MS nurse. I think MS Australia are already stretched and offer fantastic support in other areas.

I think counselling sessions would be good.

I think group sessions are a great idea...

I think this about covers it.

I would like all GP's to be given this sort of information because all I really need is a good GP, not a neurologist.

I would like MS Australia to not be involved in advertising pharmaceuticals. It is inappropriate to advertise prescription pharmaceuticals direct to the consumer. It is most appropriate that this issue is left for discussion between the treating specialist and the patient.

I would like to have some of the scientific journals / findings in relation to the oral drugs translated into laymens terms!

I would like to see all GP's better educated in regard to MS as well as the treatments no matter whether it is oral or injections

I would like to see information on the results of clinical trials made available. I would also like to know the efficacy of oral meds for primary progressive MS as compared to relapsing remitting MS.

I would like to updated on the changing risk profile. Eg, if there are increasing incidences of cancer or PML

in providing information ensure that research information is clearly explained and the details over usage by individuals

Indepth evidence based reading or audio format to enable an informed decision/choice before using the above support systems.

Info on how to get involved

Information about changing over from injections to oral ie when to change, risks - time it takes oral medication to become effective

Information about possible side effects, and details concerning effectiveness of new treatment.

Information about trials. Information about short & long term side-effects, and possible adverse impacts. Information about effectiveness in comparison to injection-based immunotherapy.

Information about impact of orals on other medications. Information on forthcoming product

releases.

Information and support are the main priorities

Information leaflets about the medication set out in case people dont have internet services to get information on would be great, in my case for my daughter

Information sessions offered by neurologists at the Nerve Centre about oral medications, open to people who have MS in order for us to ask questions and gain unbiased information. Maybe involving people who are already taking these medications.

information sessions on the different medications

Information, as I found out via other websites.

Is there relevance for Primary Progressive MS???

It would be great to discuss the options and its effects versus current treatment before discussing the possibilities with the neurologist; I always think of questions after leaving his office! .

Just a list of all side effects and things that could go wrong.

Just more information about it

Just to have someone that can really explain all the side effects and what they mean to you and how they will effect you due to the current medications that you are taking because some neurologists don't explain everything to you.

Just want to know that it is safe to use as I do not trust Tysabri and my neuro said Gilenya is made of the same stuff as Tysabri. Want to know the risks vs the pros of taking the oral meds/ ALL MS meds.

Look for a non drug based 'cure' like diet or herbs

more communication and help by MS Community Support Worker

More information based on each individuals circumstance. example: If you have a blood condition Sperocitois.

More up to date information on what options are available. I only see my specialist once a year and things change so quickly. Usually what is released in the press has been known or around for some time before I get to hear about it.

MS is too Pharma friendly and do not support other options, yes like the very positive results with CCSVI - yet you choose not to advocate for your clients - you choose to support Big Pharma so MSRA continue to get money. Tysabri has killed and damaged more lived than the 1 in 1000 still being circulated.

My nurologist must be happy that it is better than my current injections and well proven and tested

My understanding is that some if not all of the oral medications available to MS patients have the potential to exhibit more severe side effects than Betaferon. I would appreciate detailed information relating to these possible side affects being made available.

Neurologist advice

Nil

no

no thanks

No, I have been very happy with all my dealings with MS Australia on all issues and most recently the oral treatment (Gilenya) currently available.

No, just to learn more about it

No.

Non sponsored professionals pushing their vested interest above what is best for the patient which has happened with my neurologist pushing Avonex injections

Not at this stage.

not i can think of yet...

Not sure

not sure if it is right for my type of MS. I have Primary Progressive

not that is needed if one has a good relationship with heir Neurologist and can do their own research

Nurses available to answer questions about things happening which you're not sure about (is this just a side effect or should I worry??)

o

online chat forums could be effective way of communicating with a nurse/support

Pamphlet or paperwork in relation to the oral medications. A fact sheet

Peer support via the internet, not just in person or via phone.

Plain English information about how to identify and what treatment is available for side-effects.

Support and follow-up for anyone suffering side effects

Publicity so even friends and family know about its existance - they are often the first to know anyway

Referral to outside (ie non-MSL) sources of information.

Statistics on the no. of people that have been trialed with the medication, the side effects, benefits etc.

Statistics that support the effectiveness of the oral treatment, outlining the disadvantages and advantages of taking it. Starting a trial it is imperative this information is given to patients.

Support / information for family members so they are also kept in the loop

Support and information for those in country areas who might feel a bit isolated like myself, not knowing anyone else in my area with MS.

Target groups. As a young person with MS I often feel left out and that a lot of support programs like the heart health are targeted at older people, i.e. above 45 and those who do not have jobs for whatever reason. It would be nice to see some things for people like myself who are young, fit and hold full time jobs.

Telephone Education .

That Nurses are kept update with the latest information to be able to pass this on too clients

The GP

The information coming from MS Australiai could be more timely.

To give detailed information on how long it has been used for in other countries and the side effects.

The long term forecast

To help in information sharing among people who are on oral medication.

Treating neurologist & GP to be informed about oral treatment in order that the treatment is watched closely, to determine efficiency

Unbiased (i.e. non drug company sponsored) trials and evidence about effectiveness and side effects

Unbiased advice. The MS Society recieves funding from Pharmeceutical companies.

Unbiased objectivity unrelated to neurological imperatives associated with MS

Up to date information to GP'S who have MS patients.

Up to date Statistical information on patients who are currently on oral meds specifying how long they've been on it, any individual side effects, personal experience of effectiveness with pills vs injections, personal experience with any such improvement etc. I think interviewing those who are currently on oral meds or having them write their stories/experiences in the InTouch Magazine would be invaluable information for those wanting to know more about it.

Very important to keep information scientifically based, factual ad not biased. Also remember that some people aren't able to participate, due to contraindications.

Video on MSL and MSRA websites

What the outcomes have been for people using these.

would ask my neurologist for guidance first and then ms australia.

yes

yes a very clear declaration of all companies where funding for research came from "so i can quickly and easily see just how bias the research is"

Yes help on a one to one basics to give us support as it is always better to ask questions if you can relate to the person.

Yes, tell them the truth. gilenya is going to kill them, even the clinical trial proves it so!!!!!!!!!!!!!! stop lying to us

Yes. Treatment and info how effective it is tailored to an individual s particular type and state of MS