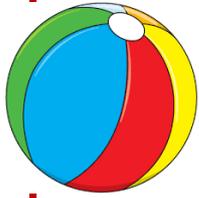




## MS Support Group Morning Tea

Meet our new Service Coordinator Sarah Klæbe and we talk to Rebecca from MS QLD to hear an update on what is planned in 2021 for our Neuro community!



Find out the latest for the upcoming Toowoomba MS Swimathon, the Toowoomba Housing Project on Hume St, what's in store for our Toowoomba Wellness Clinic, upcoming workshops and more!

Wednesday, February 17 9.45am-12noon

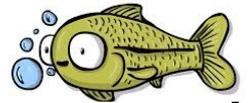
@Toowoomba Sports Club Downstairs Café

Cnr Ruthven & Russell Sts

Free Parking right of main entrance on Russell St  
9.45am Check in and be morning tea ready for 10am



**CHILL & CHAT IS BACK!** Do you want to know where and when the next Chill&Chat social meet is? So much info shared when we meet! 📞 Cathy on 0402 143 826.

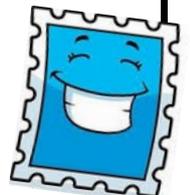


**TOOWOOMBA MS SWIMATHON SATURDAY, MARCH 6 WILL BE HOSTED IN OAKLEY!** Not swimming? You can still help to fundraise and come along and cheer on the great people making a splash for our MS and Neuro community! **Sign up/donate at [www.msswimathon.com.au](http://www.msswimathon.com.au) or phone the infoline for more info 1800 177 591.**

**MEET OUR NEW TOOWOOMBA REGIONAL SERVICE CO-ORDINATOR, SARAH KLAEBE** at our February 17 meeting or give her a call to see if she can help you in any way. **You can call Sarah on 0438 594 732 or through the infoline on 1800 177 591.**



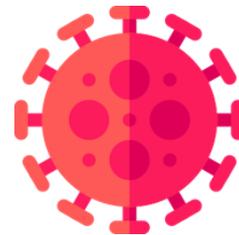
**THANK YOU GEORGE!** Thank you for your generous donation again of postage stamps to help keep us posting newsletters out, this is so much appreciated! We appreciate any donations to help thank you! If you can receive your newsletter by email instead or have changed your contact details let us know.



**THE LIFE OF DICK CHALLENGOR** was celebrated after passing away at 88 having lived with MS. Shirley, Glenda and family our thoughts have been with you. Trish Schultz also spent some special time with her mother before she passed away in November. It has been a difficult time for many.



# COVID-19 information for people with MS



Last updated: 18/01/21 (Reviewed daily) MS Australia

*This page contains general advice. We cannot make individual medical recommendations. If after reading this info you have concerns, please discuss them with your medical team (neuro, GP, etc.), your state/territory MS organisation, or contact the Coronavirus Hotline: 1800 675 398.*

*This page is updated as new information becomes available. It includes advice collated from a number of reputable sources, including an independent group of neurologists from Australia and New Zealand, and another international group led by MSIF. (MSIF's advice can be viewed [here](#).) The information below from MSIF refers to the COVID-19 mRNA vaccines (Pfizer-BioNTech and Moderna). In Australia, it is possible that we will have access to both mRNA and the adenovirus based vaccines as the TGA has given the provisional determination to the Pfizer-BioNTech and AstraZeneca-Oxford vaccines. Information will be added regarding the adenovirus based vaccine as it becomes available.*



**COVID-19 mRNA vaccines (Pfizer-BioNTech and Moderna) and MS** Our guidance currently relates to the mRNA vaccines (Pfizer-BioNTech and Moderna) only, as these have been through an assessment by our clinical and scientific experts. We know that other COVID-19 vaccines are in use in different countries, and our aim is to update our advice to cover these vaccines as soon as possible.



The mRNA vaccines work by using part of the coronavirus' genetic code to prompt a response from the human immune system, which in turn will generate a human response to produce antibodies and T-cells cells (a special population of white blood cells) to fight the virus. All data regarding these mRNA COVID19 vaccines come from clinical trials, which were carefully and thoroughly reviewed and then approved by regulatory authorities.



We do not know how many people in the mRNA vaccine clinical trials had MS, so data on the safety and effectiveness of mRNA COVID-19 vaccines specifically for people with MS are not yet available. Our guidance is therefore based on data from the general population in the vaccine clinical trials, and guided by prior experience regarding vaccination of people with MS. We will update our guidance as more data emerges.



**The mRNA vaccines (Pfizer-BioNTech and Moderna) are safe for people with MS** The mRNA vaccines (Pfizer-BioNTech and Moderna) do not contain live virus and will not cause COVID-19 disease. The mRNA vaccines (Pfizer-BioNTech and Moder-

na) are not likely to trigger an MS relapse or to worsen your chronic MS symptoms. The risk of getting COVID-19 far outweighs any risk of having an MS relapse from the vaccine.



The mRNA vaccines (Pfizer-BioNTech and Moderna) can cause side effects, including a fever or fatigue. A fever can make your MS symptoms worse temporarily, but they should return to previous levels after the fever is gone. Even if you have side effects from the first dose, it is important to get the second dose of the vaccine for it to be fully effective.

**The COVID-19 mRNA vaccines (Pfizer-BioNTech and Moderna) are safe to use with MS medications** Continue your disease modifying therapy (DMT) unless you are advised by your MS healthcare professional to stop or delay it. Stopping some DMTs abruptly can cause severe worsening of the disease. Based on data from previous studies of other vaccines and DMTs, getting the mRNA vaccines (Pfizer-BioNTech or Moderna) while on any DMT is safe. Some DMTs may make the vaccine less effective but it will still provide some protection. For those taking ofatumumab, alemtuzumab, cladribine, ocrelizumab, or rituximab – you may need to coordinate the timing of your vaccine with the timing of your DMT dose. Work with your MS healthcare professional to determine the best schedule for you.



All of us have a personal responsibility to slow the spread of the pandemic and eliminate the virus as quickly as possible. The authorisations of safe and effective vaccines for COVID-19 bring us one step closer to eliminating this pandemic. In areas where there is ongoing local transmission of COVID-19, in addition to getting vaccinated, you should refer to your local guidelines about transmission mitigation strategies, which are likely to include wearing a face mask, social distancing and washing your hands.

## BioNTech Vaccine Treats MS in Mice Without Dampening Immune System

JANUARY 11, EXCERPT FROM 2021 BY MARTA FIGUEIREDO MS NEWS TODAY

**BioNTech's experimental non-inflammatory vaccine** —

designed to dampen the abnormal immune responses seen in multiple sclerosis (MS) against myelin — delayed the onset and lessened the severity of symptoms in a mouse model of MS, a study reports.

Importantly, treated mice showed no signs of overall immune suppression, suggesting that this type of therapy may overcome the downsides associated with current immunosuppressive therapies for MS. These data support advancing this vaccine, and possibly bringing it into testing in patients. The study, "[A noninflammatory mRNA vaccine for treatment of experimental autoimmune encephalomyelitis](#)," was published in the journal *Science*.



**Research  
to watch!**

# Hello

as we flip over into the new year we hope with more knowledge and understanding that 2021 will be a year we are more confident to adapt to change. Some of you don't realise that I live with low vision due to optical nerve damage which was my first symptom of Neuromylitis Optica back in 1998 before a 2001 diagnosis of MS which evolved into a diagnosis of NMO a couple of years later. For those with low vision it is one of the invisible symptoms not recognisable to others so it is up to us to learn how to communicate when we need assistance, a challenge in itself with Guides Dogs Australia and Vision Australia low vision services opening up my world and showing me how to become more independent in my world.



My growing neurological challenges were not noticeable to others until I needed a wheely walker for mobility support a few years later but I still need to remember to share the fact I have low vision when needed so I don't appear rude by not recognising someone or am asked to read something or fill out a form etc as I don't always have my handy magnifying tools on hand and people cannot read my mind as to what I can do for myself or need help with, without good communication this can be equally frustrating for loved ones around you who only want to help. I try to do what I can or have a go first preferring to have control of my choices but try to communicate when I do need help. With a disease that can take so much independence and more from you I want to hang onto all I can to live my life in the way I possibly can. Have a go and if all fails then try and know that you can be proud of yourself for trying, just learn the wisdom and communication skills to ask when you need to.

*I apologise to those who I sent Christmas wishes to with a poo text emoji (text pic) when I thought it was a christmas tree and to a new neighbour (and his wife!) I recently sent an emoji kiss to instead of a smile! Oops!*

Hope to see some of you soon!

Jo



**M**any of us have acquired a very helpful lounge lift chair and are comforted by the fact they now come with a small battery back up so if the power goes out the person can still get out of the chair. Recently our power *did* go out and I was happy as I continued reading my magazine with my light up magnifying reader with that thought that my chair would also have the battery back up. BUT when I went to move I didn't know how to use it did I?? My husband could not find the batteries either and the chair manual said it did not come with batteries but had no diagram or mention where they were!

**Consider yourself warned!** Before the power goes out unexpectedly, make sure you know how the back up works and make sure you replace the usually 2x AA batteries every 12mths as recommended or after use.



# assistive technology explained

When they hear the term 'assistive technology', many people picture AI assistants or helper robots, but in reality assistive technology (AT) can be far more straightforward than this. According to the NDIS, assistive technology is: "[...] a piece of equipment that helps them to move around the home or community, communicate with others, or process information more easily." In other words, AT helps people living with a disability to:

- do something more easily or safely
- do something they otherwise cannot do because of their disability
- Ultimately, anything from special forks which help the participant to eat, to vehicle modifications, handrails, personal alarms, or computer software may be considered eligible AT and included in the participant's NDIS Plan so long as it:
  - Meets the participant's needs (as part of their NDIS Plan)
  - Helps the participant pursue their goals
  - Is considered reasonable and necessary by NDIS testing standards



## The NDIS has broken down Assistive Technology into four complexity levels:

**Level 1 (basic):** Affordable, low-risk items that can be easily sourced. Products typically have specific features that address functional limitations and are used for familiar activities in familiar environments. Examples include non-slip bath mats, replacement mobility canes/walking sticks, larger print labels, smoke alarms, doorbells, adapted grip equipment, and other similar items for daily living.

**Level 2 (standard):** Low- to medium-cost/risk products and services that require only minor adjustments to activities and environments. These AT products are typically available 'off the shelf' and require either straightforward training or minor adjustments before use. Examples include simple bathing and toileting devices, vision/hearing devices, orthotics, and home adaptations like handrails, ramps, and personal alarm systems.

**Level 3 (specialised):** AT is similar to Level 2 but requires either modification to cater to the needs of the user/participant, has a higher risk of injury if incorrectly set up, or the device has a greater level of usage complexity. Examples include pressure mattresses, desktop electronic magnification, power-assisted wheelchairs, non-complex prosthetics, and refreshable electronic Braille displays.

**Level 4 (complex):** This type of AT is either custom-made or configured uniquely for the user, comes with additional complexity of use, or carries high risk if improperly used. Examples include prosthetics and complex home modifications.

Some additional examples of AT can include:

- Mobility aids like wheelchairs, scooters, walkers and canes
- Hearing aids
- Cognitive aids, including computer aids or electronic assistive devices
- Computer software and hardware to help people with mobility and sensory impairments (e.g. screen readers, speech assistance apps)
- Automatic page-turners, book holders, and adapted pencil grips
- Closed captioning
- Ramps, grab bars, and wider doorways
- Adaptive switches and utensils



Important note: The NDIS does not fund AT items that are more appropriately funded by other government services. Participants can consult their NDIS provider to ensure their NDIS plan is appropriately aligned with their needs and support eligibility.

### Part 3: Prescribing assistive technology in the NDIS

Not all participants will be eligible to receive assistive technology supports through the NDIS. To gain access, the AT needs to align with the participant's objectives. Here we examine the process of creating an NDIS plan with a provider.



### The importance of goal setting

Before accessing NDIS funding, participants and their providers work together to create an individualised NDIS plan. In this plan, participants will be asked to identify their goals, as well as their challenges. Goals can range from improving speech to feeling more independent – whatever a participant wants to achieve is up to them. What's important about these goals is that they should help a participant feel they have direction and can achieve what they want in life.

Based on the set goals, the NDIS provider will assist the participant by prescribing the necessary supports. These will only be prescribed as needed to address the challenges and objectives of the individual. For example, someone living with a disability may want to feel more independent and become less reliant on a carer. To this end, the NDIS provider might recommend a Tunstall personal alarm that can be used to request help from outside the house when needed. Of course, the technologies recommended should also depend on the circumstances and capabilities of the individual.



### Further considerations for the use of assistive technologies

The upfront cost of devices can seem intimidating at first. Thankfully, most NDIS providers offer participants flexibility in managing the funded supports in their plan.....

Generally, NDIS funds can be used to, either:

- buy the assistive technology outright; or
- rent the assistive technology on a month-to-month basis



**Beyond the participant's immediate circumstances, there are a few extra factors that may need to be considered on a case-by-case basis. These include:**

**Carers:** When introducing assistive technology into someone's life, those integral to their day-to-day lives need to understand the tech. This means carers should be informed and comfortable with the technology and able to assist the participant if necessary.

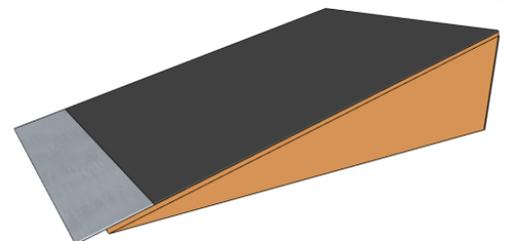
**Immediacy:** While a prescribed device must help the user achieve long-term goals, it should also make an immediate difference. Assistive technology is designed to improve everyday actions and safety for the individual, so its effect should be felt right away.

**Integration:** When a participant is living with a cognitive disability, it is possible the introduction of assistive technology may be disruptive. Working with those in their life to find a non-invasive device and introduce it with consideration is vital.

With the right supports in place, anyone living with a disability can thrive. The funding granted by the NDIS is an unmatched opportunity for carers, allied health and participants alike. With a tailored plan, a trusted NDIS provider like Tunstall by their side, and through the use of assistive technology, anyone living with a disability can achieve independence and live life to its fullest.

**Call your plan manager/service co-ordinator for more info. source.**

**<https://www.tunstallhealthcare.com.au/blog/accessing-assistive-technology-through-the-ndis?>**



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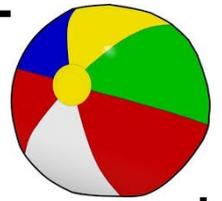
**ONLINE [www.rebenmobility.com.au](http://www.rebenmobility.com.au)**

**FIND US 2/24 Carroll Street, Wilsonton, Toowoomba**





Make a splash and enjoy a fun day out at the  
Oakey Aquatic Centre



2021 Toowoomba MS Swimathon

Saturday, March 6 from 6am-6pm

Join a team, create your own, fundraise & raise the roof to cheer on those swimming for our community living with neurological conditions!

For more info phone 1300 090 923



[www.msswimathon.com.au](http://www.msswimathon.com.au)



Electric bed owners, hide your remote from your pet after a cat and its owner woke on an electric bed with his feet heading for the ceiling after his furry friend must have laid on the remote!!



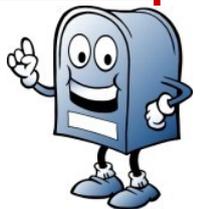
Can the support group help you with financial assistance to help you live better with your neurological condition? Our group was set up to fundraise for its own MS/neuro community for when the need/opportunity arises. Do you need taxi vouchers to attend work/social/support network gatherings or medical appointments and accomodation? Do you need help with specialist bills? We are eager to help and support you so please get in touch!



### TOOWOOMBA MS SUPPORT GROUP CONTACTS

|                        |                      |  |
|------------------------|----------------------|--|
| Support Group Convenor | Joanna ☎0448 545 880 | email <a href="mailto:tjleane@bigpond.com">tjleane@bigpond.com</a>               |
| Treasurer              | Sue ☎4564 9318       | email <a href="mailto:wulee52@gmail.com">wulee52@gmail.com</a>                   |
| Chill & Chat           | Cathy ☎0402 143 826  | email <a href="mailto:catherineupton@bigpond.com">catherineupton@bigpond.com</a> |
| Facebook & ZOOM        | Manda ☎0435 185 435  | email <a href="mailto:manda2jane@gmail.com">manda2jane@gmail.com</a>             |
| Newsletter, MSQ Buzz   | Joanna ☎4635 3281    | email <a href="mailto:tjleane@bigpond.com">tjleane@bigpond.com</a>               |
| ZOOM Social Meet       | Julie ☎0419 432 415  | email <a href="mailto:cjfree2run@gmail.com">cjfree2run@gmail.com</a>             |
| SMAC Twmba Carers Rep  | Jon ☎4635 5481       | email <a href="mailto:carajon2@bigpond.com">carajon2@bigpond.com</a>             |

"A conduit between MSQ management and people with MS, their families and carers."



FACEBOOK "MS Support Group Toowoomba"

Toowoomba MS Wellness Centre

Easternwell Building, 8-10 Russell St, Toowoomba

Colorplast Care Incontinence Phone Irene on 0423 422 318

MS QLD Physio/Neuro Assist Appointments and Infoline 1800 177 591

[www.msqld.org.au](http://www.msqld.org.au)

Spark NeuroCare Regional Service Co-ordinators

Ipswich/Toowoomba Sarah Klæbe 0438 594 732

Ipswich Sally Stevens 0408 186 690

MS Research Australia (MSRA)

Phone 1300 356 467 Visit online <https://msra.org.au>



zoom

