

# MS Update

## Autumn 2011

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## Keeping fit with Nintendo Wii



Tim is a client with MS, Tim has MS, I don't; but we both need to keep fit and active, and we've all heard the phrase "Use it or lose it". Well, we found a fun way of keeping fit and getting regular exercise – we purchased a Nintendo Wii with a FitPlus DVD.

The balance board in FitPlus tells us our weight and body mass index, and if it has gone up or down since the previous day.

There are all types of exercises depending on how active you want to be. I often start with five minutes of jogging, then some marching followed by two minutes of Kung Fu. These are all performed on the spot. Tim usually goes for the ski jump and ski slalom. I find it difficult to sit still when I watch him skiing, I end up swaying with him.

The characters and graphics are so clear and life-like on the screen, even to the cheering crowd when we achieve a high score. We each have a character on screen to

represent us so while I'm jogging on the spot in the family room, my character is jogging up and down hills in a park. Because my mind is concentrating on watching the screen and the activity shown there,

***If you are thinking that we are real "sporty" types, you're wrong. We don't even watch sport on TV.***

it's easy to forget that I'm actually exercising and being active.

Last weekend Tim & I played games of ten-pin bowling and tennis. I have no idea who won or what the final scores were but I do know we had a lot of fun, with plenty of laughing and afterwards we really felt like we'd had a good workout!

If you are thinking that we are real "sporty" types, you're wrong. We don't even watch sport on TV. The sport we enjoy on the Wii is non-



competitive, apart from trying to improve on your own score.

We still make sure we get out in the sun for walks and gardening etc but when the weather's bad, including when it's too hot outside, we can still be active.

We have now heard that the Community Rehabilitation Unit at the Royal Hobart Hospital is using the Nintendo Wii for therapy. We thought we were on to a good thing with the Wii and that has been confirmed with the news that physiotherapists encourage their clients to use it, under their guidance.

If you haven't tried using the Wii, and you get the opportunity, give it a go. It's a lot of fun, plus it can only do you good to get some great exercise together.

# CEO's Message



*“.....every Australian who lives with a disability has a fundamental right to support that is equitable, adequately funded, well-coordinated across various conditions and across geographic boundaries, and which offers the opportunity for choice and true scope for self-determination.”*

There's a light on the horizon. It's still quite some distance away and its true shape and potential is yet to really take form, but like most strong lights, it's drawing great interest. People across our nation are turning their attention to this beacon that continues to grow at some speed. Like me, they are seeking to find out more and taking steps to ensure its eventual potential impact is a positive one.

## What is it?

By now I expect that you've heard of this beacon on our horizon, the emerging details contained within the Productivity Commission's Draft Report from its enquiry into Disability Care and Support. Released in late February, the PC's draft is now open for comment over the next few months, seeking to increase community awareness and gauge support before a final submission is made to the Federal Government in June. It is proposed that the first elements of a pilot program will begin implementation in 2014, with full roll-out nationwide over the following four years. It impacts upon everyone who lives with a disability, whether this might be a lifetime condition, as in the case of MS, or a condition which has emerged through catastrophic injury. Essentially, the draft report recognises that every Australian who lives with a disability has a fundamental right to support that is equitable, adequately funded, well-coordinated across various conditions and across geographic boundaries, and which offers the opportunity for choice and true scope for self-determination.

## Do we know the details?

At the moment, it's the big picture that we can see taking shape. The PC's draft recommends creation of two schemes – a National Disability Insurance Scheme (NDIS) that is relevant to people with MS, plus the coordination of a National Injury Insurance Scheme (NIIS) for those whose lives are impacted by catastrophic injury. Importantly, both initiatives are Federally coordinated – there are strong signs that there is frustration with the legacy of many inefficient

and varied schemes which are currently state-based and that the PC has listened to the many strong submissions of stakeholder advocates, including The MS Society of Tasmania, the Neuromuscular Alliance of Tasmania (of which our Society is a member) and MS Australia. Our local team worked hard to develop and/or contribute to each of these submissions, advocating strongly for the needs of people with a progressive condition such as MS to be heard and responded to appropriately.

The scheme is destined to require double the funding currently applied through the National Disability Agreement administered by states, increasing this to approximately \$12.6 billion. However, it is acknowledged that current cost estimates are preliminary and further analysis is needed as more data becomes available. Presently, the NDIS is taking shape as something akin to Medicare, a system where eligibility criteria and access to service and supports are well-known and consistent nationwide. While further details will continue to emerge in coming months and through the further input of peak bodies and organisations such as ours, there is a strong sense of optimism that we're on the cusp of a significant change. While there is arguably still scope for more effective response to individual service and support needs in order to balance the PC's strong economic focus, this first draft does seek to put forward logical answers to complex challenges associated with funding and administration, so at least we're stepping in the right direction.

Equally, there is a commitment to ongoing research and evaluation in order to achieve the most equitable,

effective and efficient model of long term care possible. We know that our submissions and the evidence base built over many years by Dr Rex Simmons' longitudinal MS analysis has been well received. Progressive neurological diseases have been identified as primary targets for early and ongoing intervention, suggesting that those living with MS will become eligible for the highest tier of support through the NDIS from the moment of diagnosis if the recommendations are adopted. While the report is complex and its concepts often challenging to visualise in great detail at this point, the example of life with MS is projected to illustrate just how the proposed system would work and the signs of a more appropriate approach are looking favourable.

### Where to from here?

There are many opportunities to learn more and to seek to become involved. The February draft report is available online at <http://www.pc.gov.au/projects/inquiry/disability-support/draft> or you can contact our offices to arrange for a copy to be provided to you. The PC invites written submissions upon this by 30 April and there will also be public hearings in each capital city, with the Hobart forum to be held on Monday 4 April at the Hotel Grand Chancellor (registration via 02 6240 321 or through [disability-support@pc.gov.au](mailto:disability-support@pc.gov.au)). In addition to this, you may have heard of the Every Australian Counts campaign, spearheaded by John Della Bosca. Their website at <http://www.everyaustraliancounts.com.au> features an online petition which encourages you to take action by adding your name to the campaign to support independence for people with a disability and their carers. Local activity details can also be found on this site including a Hobart gathering at 1.00pm on 5 April at Parliament House, with the Launceston forum being held at the Inveresk Tramsheds on 6 April at 9.30am.

Our Society will have representation through each of these channels, ensuring that the MS voice is heard strongly. Together with our fellow State MS Societies under the national umbrella of MS Australia, we will continue to be active in defining the details over coming months and years. Our MS Australia community is supportive of the general thrust of the Productivity Commission's recommendations from its review of disability care and support, particularly the National Disability Insurance Scheme, as outlined in its draft report. However, we also understand that considerably more detailed work is now required to ensure a smooth transition. With that understanding, we welcome and encourage the opportunity for full participation and contribution at both a local and national level.

## You Raised Your Voice and We Listened!

We are delighted by your response to the recent client survey – 196 of our clients completed and returned the survey form, giving us valuable insight into what you would like to see included in Client Services Projects in the future.

The results will be carefully analysed over the coming weeks and a full and detailed report will be compiled. This report will then be made available to all interested parties through the website and also in print. A summary of the findings will also be published in the next edition of MS Update.

Most importantly, the information that the survey has given us will be used to shape the future direction of projects as part of our annual business planning cycle. It is our aim to deliver the most appropriate and helpful programs to benefit as many clients as possible within our resource base, but taking advantage of opportunities for collaborative initiatives wherever these might be available and viable.

### ***Our heartfelt thanks to all those who returned the survey!***

Our clients who returned the survey were given the chance to enter a draw for an iPod Touch. We have a feeling this may have motivated such a magnificent response and we're delighted this approach worked.

### **And the Winner Is ....**

The lucky winner of the 8g Apple iPod is Kathryn Clifford.  
*Congratulations Kathryn!*

The Client Services Team





# Australian of the Year

## Simon McKeon

MS Australia, MS Research Australia (MSRA) and the MS community congratulate Simon McKeon on being awarded the prestigious Australian of the Year Award for 2011.

Mr McKeon has been committed and dedicated to the MS cause and was subsequently awarded the MS Australia John Studdy Award for 'outstanding consistent and selfless provision of meritorious service to people with MS' in October 2010. The award recognised his key role in the establishment of MSRA in 2004, and his ongoing leadership role. Mr McKeon, who was diagnosed with MS 10 years ago, is also a past Chairman of the MS Australia Board. He recently retired as founding chairman of MS Research Australia, taking up a new appointment as Chair of CSIRO.

"Simon has guided and inspired MSRA to a position as Australia's peak body for MS research and made it one of MS Australia's most successful research-based initiatives," said MSRA Executive Director Jeremy Wright.

Mr McKeon, who is the Executive Chairman of Macquarie Bank's Melbourne office, has been a shining light in the philanthropic world for many years. His many other humanitarian and philanthropic activities include being a Director of World Vision for 15 years, a director of the Global Poverty Project and working directly with heroin addicts and remote indigenous communities.

Not only is Mr McKeon a prominent investment banker and philanthropist, he is also a world record breaking yachtsman. Together with crewman Tim Daddo, he has held the World Speed Sailing Record for most of the last two decades.

Mr McKeon demonstrates how business and philanthropy go hand in hand, giving tremendously of his time and energy to many organisations. An inspiration to all Australians, we congratulate Mr McKeon and thank him for his dedication and commitment to helping Australia, the world and the MS community most particularly.

# The 50 and BETTER CENTRE

The 50 and Better Centre offers a wide range of social, recreational, cultural and educational activities for people over 50 in a warm, welcoming and safe environment.

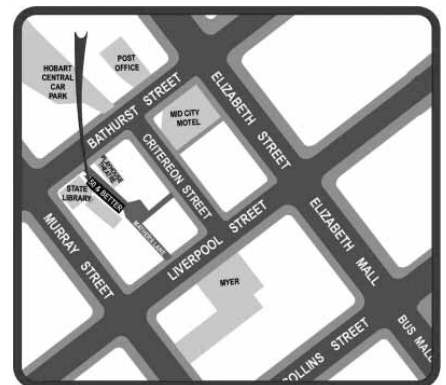
The Centre is provided by the Hobart City Council and is located at 108 Bathurst Street in Hobart, with level access at the front entrance and accessible toilet facilities also.

Low cost lunches are provided from Tuesdays to Fridays, and light refreshments are available on Mondays. The Centre provides activities such as:

- Zumba
- guitar lessons
- a laughter club
- Tai Chi
- a range of craft activities and more.

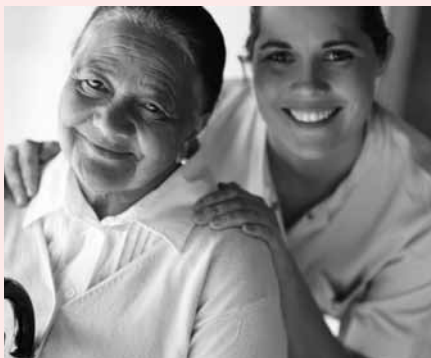
Free cinema is also held on Fridays at 1pm!

If you would like to subscribe to the centre's newsletter to find out what activities are coming up, please email [walkerd@hobartcity.com.au](mailto:walkerd@hobartcity.com.au) or call the centre coordinator on 6234 1441.



# Research Update

Sue McGregor



## Royal Hobart Hospital MS Clinic



If you would like further information about the trials, please contact Sue McGregor through the MS Society of Tasmania.

The CARE MS trials (CAMMS 323 and 324) compares two annual cycles of intravenous Alemtuzumab to three times weekly subcutaneous interferon beta 1a amongst treatment naïve patients (those who have not previously received any disease modifying therapies) with relapsing remitting MS or in patients with relapsing remitting MS who have relapsed on therapy. This long running program has been progressing very well with all patients remaining on trial and many now having completed two years of commitment to the research.

Those patients who have reached the 24 month time point have now been offered the opportunity to participate in the CARE MS extension trial (CAMMS03409) which provides patients the chance to have a further infusion of Alemtuzumab if clinically indicated. For those patients who do enrol in the extension trial, it will bring their total commitment to six years – what an amazing achievement!

We are still recruiting patients for the CIS (clinically isolated syndrome) trial known as TOPIC, where patients are treated

with either 7mg or 14mg of Teriflunomide once daily versus placebo. It has been a very slow trial to recruit patients globally and the enrolment period has been extended indefinitely at this stage to allow numbers to build. Tasmania has recruited only one patient but of course we seek more and encourage further queries.

Two further trials are taking place for patients with Primary Progressive MS (PPMS) in Tasmania. These are the INFORMS trial – comparing the efficacy and safety of 0.5mg Fingolimod (FTY720) administered orally once daily against a placebo. So far we have recruited three patients, with one now commencing treatment and the other two in the screening phase.

The second trial for patients with PPMS is another phase 3 trial comparing the safety and efficacy of Ocrelizumab compared to a control placebo. It is anticipated that this trial will commence recruitment in late March/early April, and as always, while participants are actively sought by our local researchers, we encourage any queries.

# Do it mate, do it now!

Elizabeth Neal



*“do you want to get a bus and go around Australia? Or is this just my dream?”*

My partner William has had a dream for a long time to take me and our two children and travel around Australia in a converted bus. When he wanted to buy his brother's rather badly converted bus that he had no further use for, I said in no uncertain terms, “no way!”

But for me, my MS is worse when I am cold. So, as time went by, I found myself longing for the warmer weather of the mainland where I grew up. Whenever I would say something like “let's all go to Darwin for a few months,” William would reply “If we had a converted bus that would be easy to do”. So I was starting to think this may be a good idea after all.

The deciding factor came in June 2010. William met someone who would change our lives. William had a chance meeting with a Carer of a person who has MS. They too had a dream to go around Australia in a motor home. So not long after diagnosis they did just that and had the time of their lives. However, the pivotal words that resonated with William, and would catalyse him into action were “Do it mate, do it now. Even without MS, you never know.”

After that chance meeting William came home ‘changed’ and asked “do you want to get a bus and go around Australia? Or is this just my dream?” I was unsure, but had to admit I had been in Tasmania for 13 years and I would love the chance to be warm again. If the bus was the way to do this, it sounded like a good thing to do, not to mention that it would be such an adventure for our children.

What initially started as a five year plan, turned into an 18 month plan and then an ASAP plan. So William went off on a tangent and started looking for a bus and began researching how to convert it and where to go to buy the parts needed. He also joined the CMCA - Campervan and Motor-home Club

of Australia. We decided to sell our house – it turned out this was our only option to finance our adventure.

The house went on the market on 10 December and it sold on the 11th – that's right the next day. Turns out the day the man came with the ‘for sale’ sign coincided with a couple driving past our house at that exact moment. The same couple had looked at the house six years ago, when we had bought the house, beating them to it. The next day we had the contract.

Our settlement day approaches and the bus is now busily being worked on by William. I struggle with the enormous job of packing, giving lots of our useful stuff to opportunity shops and friends and putting the items we cannot part with in the container.

William finishes work on 11 March, we leave the house on 6 April and shortly after this we set off on the adventure of our lives!

We often think of that person who catalysed us to this point and often tell the story of that day in June last year. We owe them a great thanks for their story and for urging William to – “do it mate, do it now!”

# MSfest 2011



14,000 young people converged on Launceston for the 2011 MSfest on Saturday February 26. The line up was fantastic and all acts put on a great show. The MS marquee was a great success with MS Staff and volunteers meeting many members of the young crowd on the day and sharing the MS message with them.

In a 2 for 1 offer, clients who purchased tickets to the event through The MS Society of Tasmania also obtained a free ticket for their carer, and an accompanying letter which allowed both our client and their carer to leave and return to the venue throughout the day. We had 12 clients take up on this offer and we hope they enjoyed the music and atmosphere at MSfest.

To increase awareness of Multiple Sclerosis among MSfest patrons, The MS Society of Tasmania, along with the support from MSfest organisers, launched "Fundraise your way to MSfest" as a new fundraising initiative. Interested patrons were asked to register and fundraise \$200+ for The MS Society of Tasmania in order to receive a ticket to MSfest 2011. We had 3 individual girls, one male and a team of 3 girls all fundraise their way to the event and just over \$2300 was raised along the way. First prize of a helicopter ride to the festival was won by Lauren Wilson who raised \$760. Well done Lauren! Lauren held numerous fundraising initiatives to help her win the first prize including a raffle, guess the number of lollies in the jar and an all you can eat and drink party. Lauren said "I had so much fun, from the moment we rocked up at Tasmanian Helicopters until MSfest finished that night. It was such an amazing day, thank you so much for organising the prizes, they were unreal!"

**For a full wrap up on the 2011 MSfest please see the website [www.msfest.com](http://www.msfest.com).**

Registrations for **Fundraise Your Way to MSfest 2012** are already up and running at <http://msfest.gofundraise.com.au/>

Organisers have declared MSfest 2011 a great success and preparations are underway to make 2012 bigger and better yet.





## Community Fundraisers

In recent times we have been fortunate enough to have many schools, organisations and businesses support the work of our Society by making generous donations.

The decision of these groups to support those living with MS demonstrates strong community spirit and also an understanding of the dramatic effect that this disease has upon communities across Tasmania.

The MS Society provides nursing care, counselling support, information and resources to those affected by MS across the State. We are also committed to supporting our research partners in their search for a cure.

The thoughtfulness and generous support of these community donations will help us to continue this important work and they should be commended for their efforts.

### Sincere thanks to the following:

- The Fahan School Students
- St Helens District High School
- K Mart Launceston
- Wrest Point Hotel Casino
- Andrew Walter Construction
- Scottsdale Primary School
- Centrelink Staff Community Fund
- Polytechnic Alanvale Campus

*Please accept our heartfelt thanks for your kind donations.*



## the novel challenge

With 2010 its inaugural year, The Novel Challenge raised almost \$100,000 nationally for people living with MS. So The Novel Challenge is returning for 2011 and with your help we hope it will be even bigger this year!

The Novel Challenge provides a fantastic opportunity for adults, book clubs, and community groups to get involved and help raise funds for the 20,000 Australians living with MS.

### TO TAKE PART:

- Register online at: [www.thenovelchallenge.com.au](http://www.thenovelchallenge.com.au)
- Select a book challenge
- Read for 30 days
- Seek sponsorship from friends, family, and colleagues!



the novel challenge

You can register as an individual or create a team from amongst your work colleagues, book club, sports team, mothers group, friends or even family.

Many of us lament the fact that we simply don't have the time in our busy lives to read as much as we would like. The Novel Challenge presents a great opportunity as an excuse to get in that valuable reading time whilst raising money for a great cause.

**For more information contact Stacey at the MS Society of Tasmania on 6220 1111 or email [stacey.king@mstas.org.au](mailto:stacey.king@mstas.org.au)**



*So book worms,  
save the date and  
read for a reason!*

# MS Readathon

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

## The MS Readathon is back for 2011!

Now in its 32nd year, Students are once again encouraged to read for a reason from 1– 30 July.

Through a new relationship, all those schools who have 10% of their students registered and each raising at least \$10, go into the draw to win 10 Apple iPads! These schools also get 10% of the funds raised back to spend on products at Target stores.



**PLUS**  
this year  
participants  
can choose  
their own  
rewards!

With great incentives like these, a world of books just waiting to be discovered and proceeds going to a great cause, there has never been a better time to pick up a book!

**Registrations will open in April at [www.msreadathon.org.au](http://www.msreadathon.org.au).**

For more information please call Stacey on 62220 1111 or visit [www.msreadathon.org.au](http://www.msreadathon.org.au)

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## Local Council Disability Contacts

We have a comprehensive list of local council disability contacts on our website. If you have any questions or concerns about local council disability or access issues please use this list to guide your contact to the relevant council in order to speak to an appropriate person.

To access this list:

- visit our website at [www.mstas.org.au](http://www.mstas.org.au)
- select **How You Can Help** from the menu on the right hand side
- select **Council Contacts**

Alternatively, the direct URL is:

<http://www.mstas.org.au/how-you-can-help/council-contacts/>



**The MS Society of Tasmania has just held its inaugural 24 Hour Mega Swim in Hobart! With plenty of teams and participants and a good time had by all, the event was a great success.**

**We are now holding the events in Ulverstone and Launceston:**

**EAST ULVERSTONE POOL:**  
12pm Saturday 28 May – 12pm Sunday 29 May 2011

**LAUNCESTON AQUATIC:**  
12pm Saturday 25 June – 12pm Sunday 26 June 2011

The 24 Hour Mega Swim is a great event for all ages and abilities. It doesn't matter if you can do 100 fast laps or just doggy paddle one, everyone can join in, have fun and help spread awareness about the impact of multiple sclerosis.

Teams of up to 15 people swim relay style for the 24 hour swim period. Teams can consist of all ages and be single or mixed gender. During times when team members are not swimming, food, drink and entertainment will be available on site, helping to sustain them while cheering on fellow team members in the pool.

Funds raised at the Mega Swim will allow Tasmanians living with MS to apply for Go for Gold Scholarships, that will assist them in following their dreams whether these might be focused upon sport, the arts, education, travel or other areas.

**Visit [www.megaswim.com](http://www.megaswim.com) for all the event details!**

## Starring Staff Profile



**Lynsey Spaulding**  
*Case Manager*

**Date Joined the Society:** April 2005 **Interests:** Reading, Shopping, Gardening & Travelling **Favourite Food:** Nachos  
**Favourite Music:** Muse **Favourite Book:** Bridget Jones Diary or anything by Stephen King

**Background:** Lynsey grew up in Hobart at Clifton Beach. She attended Lauderdale Primary School going on to Clarence High and then the University of Tasmania where she did a Bachelor of Arts in Psychology and then a Graduate Diploma in Rehabilitation Counselling.

She has previously worked for Edwards Windsor Real Estate and Steps Employment before joining the Society in 2005 as a Case Manager. Lynsey has a special interest in employment issues, supporting our clients, their families and carers and connecting them with various services and sources of information. Her expertise, professionalism and enthusiasm make her an integral part of our Client Services team.

Lynsey enjoys travelling and has so far been to Egypt, Singapore, China and Hong Kong. She has recently become engaged to Geoff and they will be married in November of this year after which they would like to do some more travelling. They have also recently purchased a home in Sandford that they share with Paulie the cat, the girls (chooks) and soon (once the fences are in place) 26 year old Chester the horse, who Lynsey has had since she was 12 years old. We would like to wish Lynsey all the very best for her upcoming wedding and future travels.

FREE SEMINAR



MS AUSTRALIA  
Giving life back



# Information is Power SEMINAR SERIES

**ABOUT THE SEMINARS:** Leading health professionals, including case managers, counsellors and nurses from the MS Society's Client Services team, other allied health professionals and a solicitor from the community legal services will deliver the seminars. There is no charge for participating in the seminars, which have been generously sponsored by **Biogen Idec Australia Pty Ltd.**

### TOPICS

- Exercise for Health and Wellbeing:  
*Guest Physiotherapist*
- Eating for Good Health: *Guest Dietician*
- Stress management and dealing with emotions
- Employment issues, including disclosure to an employer and disability discrimination:  
*Guest Solicitor*

### HOW TO REGISTER

To register for the Information is Power seminar in your region, call Di Russell-Green on 6220 1111 or email [aboutus@mstas.org.au](mailto:aboutus@mstas.org.au).  
Please register by 30 March 2011.  
Feel free to bring a support person if you wish.

### HOBART

**Date:** 6 April 2011  
**Time:** 10:00 – 15:00 (Registration from 09:30)  
**Venue:** The Baha'i Centre of Learning  
Cnr Brooker Ave and Tasman Highway, Hobart

### LAUNCESTON

**Date:** 14 April 2011  
**Time:** 10:00 – 15:00 (Registration from 09:30)  
**Venue:** The Tailrace Convention Centre  
1 Waterfront Drive, Riverside

### ULVERSTONE

**Date:** 27 April 2011  
**Time:** 10:00 – 15:00 (Registration from 09:30)  
**Venue:** Ulverstone Surf Life Saving Club  
Beach Road, Ulverstone

This Seminar is open to ALL clients of the MS Society.



**AUSTRALIA**  
Giving life back

## Head Office

### Hobart

15 Princes Street  
Sandy Bay TAS 7005  
Tel: 03 6220 1111

### Northern Regional Office

18/2 Innocent Street  
Kings Meadows TAS 7250  
Tel: 03 6343 1240

### Freecall

South: 1800 676 721  
North: 1800 654 872

[www.msaustralia.org.au/tas](http://www.msaustralia.org.au/tas)

## Main North & North-West Support Groups

**Enquiries: 6343 1240**

### Launceston Support Group

Meets the 2nd Thursday each month at the Branch Community Centre next door to the MS Society Office (opposite the bowling alley).

18/2 Innocent Street, Kings Meadows  
Time: 11am to 1pm

### Ulverstone Support Group

Meets the 4th Wednesday each month at the Ulverstone Surf Life Saving Club, Beach Road, Ulverstone (Lift access is available)

Time: 11am to 2pm

### Circular Head Support Group

Meets the 1st Monday of each month at Circular Head Rural Health Services Inc 68 Emmett Street, Smithton

Time: 7.30pm

Contact Jenny on 6452 1594

## Southern Support Groups

**Enquiries: 6220 1111**

### Eastern Shore Support Group

Meets the 2nd Friday each month at Bellerive Yacht Club (entrance to function room off lower car park).

Time: 10 am to 12 noon

### Glenorchy Support Group

Meets the last Friday bi-monthly at Glenorchy Community Health Centre, Meeting Room 3 – 1st Floor, Terry Street, Glenorchy.

Time: 10.30am – 12 noon

Note: Some days may change due to public holidays (please check your calendar).

## Follow us online



### FACEBOOK

Search for The MS Society of Tasmania to find our page



### TWITTER

<http://twitter.com/MSTASMANIA>



### YouTube

[www.youtube.com/MSSocietyAustralia](http://www.youtube.com/MSSocietyAustralia)