MSlife



CONTENTS

Ready for a nap, but the desk is in the way?	1
Hello Yello inclusive clothing	5
Ursula's story	7
Jodie's healthy cooking	10
Parenting and MS	12
My diagnosis journey: a partner's perspective	14
Heat and MS	16
Farewell to Helen Dell	18
Welcome to my world poem	20
Travelling with Beth	21
Finding quality of life with incontinence	23

FROM THE MS QUEENSLAND TEAM

Welcome to your Summer/Autumn edition of MS Life.

We hope you enjoy the stories, lifestyle tips and advice. Like always, we aim to bring you content from the community, for the community.

We recognise that the average age of an MS diagnosis is just 30 which is often a stage in people's lives where they're considering starting or have just started a family. That's why in this edition, we bring you Rachel Kerr's story. Rachel kindly shares her experience of parenting and MS, and her partner Shannon shares his experience of a partner's journey through an MS diagnosis and beyond.

We've also got stories about what the NDIS has done to help Ursula Lockwood and we also tell the story of Hello Yello inclusive clothing; how a Brisbane woman is changing the fashion industry by creating fashionable clothes for people living with disability.

We hope you can sit down with a cool drink and enjoy reading through this edition of MS Life. As always, your feedback is welcomed so please don't hesitate to send us an email with any feedback, tips or if you have a story to share.

The MS Queensland Team



Email the MS Queensland Team on hello@msqld.org.au

READY FOR A NAP, BUT THE DESK IS IN THE WAY?

How to manage fatigue for better work, rest and play!

Fatigue is one of the most common symptoms of MS, occurring in approximately 80% of cases. It can interfere with participation in all aspects of life, particularly a person's ability to work.

The good news is that you can take steps to lessen its impact on your daily function and participation in work. Having a good understanding of what causes your fatigue, how it works and what strategies work for you to manage and lessen it is a good place to start.

Through our work in supporting people with MS to remain employed, we have found that managing fatigue is usually dependent upon the person making some small changes to routines, priorities and activities.

Small lifestyle changes enable a person to do more, not less.

Many of the changes that work for a person to manage their MS fatigue are good lifestyle practices that also contribute to managing other MS symptoms and improve general

wellbeing too. So what is there to lose? Why not consider how some of these strategies could fit into your life?

DID YOU KNOW

Neuromuscular Fatigue is a failure of damaged nerves to conduct messages to muscles during repetitive or prolonged activity and can usually be resolved with a short rest break. For example, your hands may tire during typing, but function will recover after a rest break.

Lassitude Fatigue is an overwhelming sense of tiredness that can occur any time without warning, and sometimes with no apparent reason. It does not necessarily resolve after rest. In addition to these types of fatigue that are a direct result of MS, there are also the secondary causes of fatigue. This may be sleep disturbance due to pain; muscle spasms; low mood; and as a response to temperature insensitivity.

Checking in with your fatigue

The first step in making changes to lessen your fatigue can be understanding your own experience of it better.

- Keep a fatigue and symptom diary for a week or two, and see what
 patterns emerge. Write down your activities, symptoms, what time
 you have gone to sleep what time you get up and if you have had rest
 breaks or naps during the day.
- This can give you valuable information to use in planning when you carry out activities, when you need to rest or what activities particularly contribute to fatigue.
- Once you have this information, think about how you might use some strategies to target your fatigue.

Monitoring fatigue and rest at work

To get the most out of your energy throughout the work day, consider your duties from these perspectives:

- **Task** | How can you change the way you complete work tasks to make them less fatiguing? Can a more intense heavier task be done earlier in the day when you have more energy? Are there tools or equipment that can make the task easier to perform? Can a task be broken into smaller components and done 'a bit at a time'?
- Environment | How can you change or adapt your work environment to make it less fatiguing?
- Consider energy conservation techniques | For example, doing all of the printing in one go and collecting it all together; or choosing a desk position that limits how far you need to walk to the printer/staff room/ bathroom.
- Environment & body mechanics | An ergonomically sound workstation will reduce energy that is lost due to poor posture or poor muscle efficiency. Limit your exposure to high or low temperatures. If the air conditioning isn't adequate, think about personal cooling aids that may assist. From small desk top fans to cooling attire (such as cooling vests) there are a range of products that can reduce the impact of fatigue caused by temperature insensitivity.
- You | How can you change your personal practices for any normal daily activities to maximise energy levels for your work day? For example, sitting whilst showering or dressing before work may leave you with more energy.

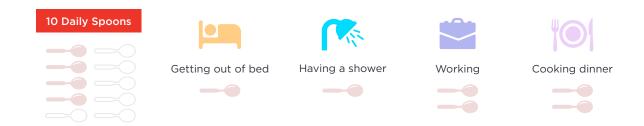
Rest and Sleep

You may have heard the term 'sleep hygiene'. This refers to the routine we have around going to bed and sleeping. Practising good sleep hygiene helps to improve the quality of the sleep and rest that you get, and contributes to you waking feeling refreshed. A good sleep hygiene routine includes:

- Avoiding caffeine, alcohol and other stimulants prior to bedtime
- Having a regular sleep/wake pattern e.g. going to bed and getting up at a similar time each day
- Participating in calming activities before bedtime. You may consider using mindfulness techniques or meditation to achieve a state of calmness
- Making your bedroom a comfortable and calm place for sleep e.g. have the room at a comfortable temperature

Spoon Analogy

Visualise that you have 10 spoons of energy per day, and every task uses one spoon. This helps you to prioritise and plan activities each day by considering the impact of each task, and which are the most important to you.



The Three Ps - Plan, Pace and Prioritise

Consider all of the things you do in a day/week, and apply this principle. Think about what is most important to achieve, and when best to do it (when you have the highest levels of energy). Delegate tasks when you can, and 'dump' those of low priority.

Exercise and Lifestyle

It is easy to give up on exercise when you are feeling constantly tired and fatigued. But, participating in regular exercise actually improves endurance and increases energy levels. It also improves your mood and helps to manage stress. Low mood or anxiety can contribute to fatigue, so exercise is doubly effective in increasing your energy levels.

Keeping hydrated and eating healthily will also improve your energy levels.

Rest Breaks

Build small rest breaks into your daily routine. Take a few minutes to stretch; go for a walk around the office (or block); go to fill your water bottle; use headphones at your desk to eliminate distraction. Find a quiet place (unused office/meeting room/car) that you can spend a few minutes recharging. Changing your posture and taking a cognitive break from a task can provide some rejuvenation.

If you can, build rest breaks into your week. If you work part-time, it may be good to have a day off in the middle of the week, then you can participate in rejuvenating activities to build up your energy.

By implementing small changes (even just one or two) in home and work activities, you will be saving your energy for the tasks that you consider the most important for you to do. If you need help with making changes for working with MS, the MS Queensland employment support team can help.

Want to find out more about MS Queensland's Employment Support Service?



https://www.msqld.org.au/service/employment-services/

Article credits to MS Australia





HELLO YELLO INCLUSIVE CLOTHING

We recently sat down with Charlotte Coory who despite juggling three young kids and her busy work as a family lawyer, decided to take a leap of faith and start an inclusive clothing brand. Inspired by her sister's struggles to find appropriate and fashionable clothing in the final stages of her terminal illness, Charlotte is now working full-time on Hello Yello Clothing and we're excited about what the future holds.

Tell us a bit about Hello Yello and how it came about...

Hello Yello is an inclusive clothing online store. It's inclusive because all the clothes are mainstream designs but also include another section of society that's not usually included by the mainstream fashion industry – people with a disability or different need. For all of the clothes that I stock, the first consideration is "Is this fashionable? Is this something you would buy in a mainstream store?"

When my sister was sick she found it difficult to find clothes that she could dress independently with and that she just liked.

My sister had a PICC line which made putting tops on and off difficult. She also had a G-tube coming from her stomach. As a result, she couldn't wear conventional pyjamas as the tube from her stomach would get caught on the waist band of the pyjama bottoms.

So I decided to shop around! I confidently told my sister I would be able to find pyjamas on the internet that would fit her needs – after all you can find anything on the internet. I tried to adapt a few pairs of pyjamas for her, without much success. But pyjama design was only one part of my sister's wardrobe which needed a rethink.

We were astounded. Finding clothing that was not only practical but that my sister actually liked was a major struggle. During our search, we became even more surprised by the lack of clothing that was available for people who did not 'fit the norm' more generally.

Where did you start?

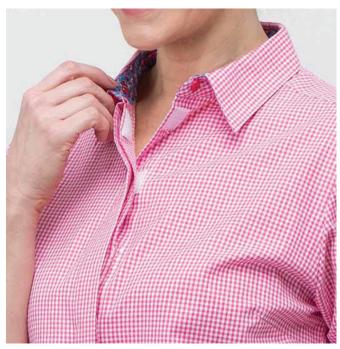
There's a lot of clothes I could have stocked but I wanted to ensure that the clothes I stocked were the most useful so one area I focused on was clothes that people could wear in the workplace.

There's research that shows clothing can be a barrier to finding work and especially for people living with disability who may struggle to find appropriate clothing that fit the office dress code but that fits their body.

I also stocked clothes for people who had limited dexterity; this includes a broad range of people. Many of the clothes stocked







Charlie Pure Cotton Gingham Long Sleeve Velcro Shirt

by Hello Yello Clothing allow people with dexterity issues to dress independently and to go to the bathroom without having to undo multiple buttons or zips. For example, we have hook and loop and magnetic closures but they're not visible.

Where did the name come from?

I wanted a brand that had the feel of a mainstream clothing store. I didn't want to create a brand that defined people by their disability but included their disability. Yellow is a fun, happy, light and positive colour which represented who we wanted to be. The name 'Hello Yello Clothing' is inclusive and welcoming to all.

What's the dream?

I'd like it to become a department style store where anyone can shop but one where people with different needs can search by categories of need as well as style of clothing. I'd love Hello Yello Clothing to be a boutique store within a fashion industry where inclusive clothing for people with different needs and abilities has become mainstream. Where you can walk into Kmart or Target and you can simply buy

an item which accommodates people with a disability or different need. Including a variety of closures, such as hook and loop technology and Velcro, will enable stores to sell their clothes to a broader market, by including people who have limited dexterity.

More about Hello Yello.

Charlotte also has a pre-loved clothing store on her website where you can find/donate inclusive clothing that you may no longer need. You can also get in touch with her if there's an item of clothing you're looking for and she'll be happy to help. There will be no cost to you as she was generously donated some Australian Post express post bags.

Charlotte has kindly offered a unique discount code for the MS Queensland community.

Use the code 'MSQLD' up to 29 March and get 10% off all clothes in the <u>adult range</u>.



Visit Charlotte's store at **helloyelloclothing.com**



URSULA'S STORY

We chatted with Ursula, a star fundraiser and magnetic personality at MS Queensland, to learn more about her journey with MS and the effect it's had on her outlook on life.

How long ago did you start experiencing symptoms and what were they?

I was in my late 20s with everything to look forward to in life. I was just married with a baby son, I had a job that I loved, and a young family just starting out. But then the symptoms began...strange and scary symptoms that I'd never felt before:

- Numbness in my right leg, odd tingling sensations, electrical shock like symptoms
- Odd sensations on my skin

I knew something was very wrong but couldn't explain what was going on. Months later after what seemed like forever, I finally received the diagnosis. Bringing up my baby boy was not easy, with regular visits to hospital and trying to manage the household.

What was your reaction when you were diagnosed, and do you remember what the doctor/s told you?

I knew it was a neurological problem. I was relieved when I found out as I had been having symptoms for a few years.

Has your condition stopped you doing things that you used to?

I have taken part in two big physical (and now I realise mental challenges) by participating in a bike ride through Cambodia and a trek in Ladakh. Ever since I was diagnosed, I have always challenged myself.

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Would you say your life has changed since your diagnosis? If yes, how?

For the better. I have met so many other wonderful people. I have empathy. It made me want to help others.

My husband has been with me every step of the way. He is my knight in shining armour. The one person that sees and lives with this daily. My beautiful son has only ever known me to have MS and has supported me all the way.

Do you have a motto or quote that you live by?

Back on ya bike!

Has MS Queensland helped you during your journey?

I have been involved with MS Queensland for a long time. Ever since being diagnosed, I have been involved in different fundraising initiatives.

I work every day to stop the disease progressing through exercise, medication and through diet. I have worked to get greater mobility and strength. It is very important to me to keep on moving. If and when I need information or support, I contact MS Queensland, like when I had so many questions about the NDIS.

Initially, I didn't really understand the importance of the NDIS and didn't have any idea that I would get the help I have now. I only heard negative stories, so I thought I would just leave it. From volunteering at MS Queensland, I saw the importance of the NDIS and talked to MS Queensland about the NDIS and they talked me through everything.

In the beginning it was daunting, even scary and confusing but we worked together to get all the relevant information and I applied. I was approved. I know that isn't everyone's experience, but you just have to keep on working through it because I want people to know how much the NDIS has changed my life and can change yours.

I get help with many things that I struggled with. Things that made me feel guilty that my husband had to do. How MS made me feel like I wasn't pulling my weight at home. The NDIS has given me the funds to pay for supports that I never even understood I needed. They have made such a difference to my everyday life and to my relationship.

I now feel I can contribute more to my family life. Having the NDIS makes such a difference to me. Things like 'cleaning' in my plan makes so much difference to my fatigue and helps me so much every week.

Anything else you want to add?

Don't be afraid to make that first call to MS Queensland. They have helped me uncover a life I never knew I could have. MS Queensland has a 1800 number so there aren't any excuses to contact them for any query regarding NDIS or any other query about living with MS. MS Queensland are there to help they help so much. You just have to make the call.

Email our NeuroAssist Team on info@msqld.org.au or call 1800 177 591

JODIE'S HEALTHY COOKING

Jodie was just 17 when she began getting pains so intense she could barely move her eyes. It took six frustrating years for Jodie to get her MS diagnosis and it forced her and her partner Robert to make some tough decisions.

Jodie gave up her stressful career as a chef and channelled her knowledge of food and cooking into creating healthy recipes.

Jodie has her own blog where she shares her experiences with MS and amazing creative recipes. Jodie has been kind enough to share another of her recipes with us.

Chocolate Granola

Ingredients

- 750g of rolled oats
- 1/2 cup of honey/maple syrup
- 1/3 cup of nut butter (cashew, almond etc.)
- 1/4 -1/3 cup of raw cacao powder (depending on how chocolatey you want it)
- 1/4 cup of hemp seeds
- 2 tbsp. of sesame seeds
- 1/2 cup of cranberries
- 1/4 cup of pepitas

Instructions

- 1. Preheat oven to 160 degrees Celsius and line a baking tray with baking paper.
- 2. In a bowl mix together oats, cacao, nut butter and your choice of liquid sweetener.
- 3. Pour contents of bowl onto lined baking tray and bake until toasted. Remove from oven and cool.
- 4. Once cool add remaining ingredients and give a really good mix through.
- 5. Place in an air tight container and eat when desired.







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PARENTING & MS

MS Queensland Ambassador, fundraising extraordinaire and mum of two, Rachel Kerr has kindly shared her MS experience from a parenting perspective. Diagnosed as a young teenager, Rach faced the questions that many face about the decision to have children and how she would manage her MS symptoms whilst being the best mum she can be.

You were quite young when you were diagnosed with MS, had you thought about whether you wanted kids?

Not really - I was barely 17 at the time of diagnosis, I didn't often think too far into the future!

How did your MS diagnosis affect your thinking about having kids?

I questioned whether I would be able to provide the kind of life that kids deserved - in the end though, I realised none of us know what is around the corner.

What was the reaction of people around you? Did anyone question you about having kids and living with MS?

Not to my face - haha. I am sure there were people who worried about the impact on me, both immediate and future but I am headstrong and commit to my decisions so anyone who knows me well enough to be concerned would also know me well enough to know that I wouldn't change my mind once I had committed.

How do you juggle two little kids and the symptoms of MS, especially the fatigue?

Good question - most days I have no idea how I do it either. Honestly, my husband is brilliant and picks up a lot of the slack - he ensures that the kids are getting out and about, enjoying their childhood while I still get a chance to catch a nap most days that I am not working.

How do you explain your MS to the kids? Do they understand?

I adjust it according to their age/level of understanding. At the moment, they don't know any different - their life has always been Mummy in and out of hospitals/doctors and forever getting a needle for one thing or another. They know it makes me tired and sore and my legs don't always work properly, but it doesn't seem to concern them since it's all they've ever known.

What would you say to others living with MS, both men and women, who are considering having children?

It worked for me - but you need to consider your individual circumstances to see if it is going to work for you. Make sure you have a multi-layered support network, it makes things easier. I decided to have kids because I couldn't predict the course of the rest of my life any better than I could predict the course of my MS.

Do you have any parenting and MS tips you want to share?

I wish I felt competent enough to share tips - I am winging it day by day! But they are fantastic kids who are kind, compassionate and thoughtful so I like to think we are doing something right. For people who have MS and kids, try to get a break for yourself every now and then. You can't parent effectively when you are running on empty yourself.





MY DIAGNOSIS JOURNEY - A PARTNER'S PERSPECTIVE

Shannon is the quiet and supportive husband behind Rachel Kerr. He's been with Rach from when she first had MS symptoms to diagnosis and now as a busy dad of two. Shannon generously agreed to share his journey with MS from a partner's perspective.

What do you remember of Rach's first symptoms and her eventual diagnosis?

I went to pick Rachel up from work and she was completely blind - while I was driving home she couldn't see the traffic or surrounds. Regarding diagnosis, I remember we were taken to a small hospital room at Royal Brisbane Women's Hospital and told that she had MS and was given a list of things that she wouldn't be able to do in ten years time - we were told she definitely wouldn't be working or walking in ten years. That was 14 years ago now.

What were some of the things that ran through your head when you heard she had MS?

Honestly, I had no idea what MS was - so I spent a lot of time wondering what it was and what our life was going to look like in the future. I definitely didn't understand the disease.

How has MS changed your life?

I don't really know - we were both so young, so it is impossible to know what life would have been like without it. If anything, we have met some incredible people in the MS Queensland community that we are eternally grateful for.

If you could change one thing about MS what would it be?

I would make it curable and with no nasty side effects!

Obviously, you live with MS every day as well, how does it affect you personally?

It doesn't - have you met my wife?? Determined is an understatement!

Are there any services/support you wish existed for partners of people living with MS?

Not really - I feel like in the internet age we have ready information access at our fingertips.

What would you say to a person whose partner has just been diagnosed with MS?

It isn't the death sentence that it used to be painted as, and personally, I would tell them to be aggressive early with their treatments (obviously in line with their medical recommendations!). I would tell them to read about it, take in as much information as they can, and definitely learn to listen.

Just don't be afraid to ask for help and make sure you find a medical team you can talk to.



HEAT & MS

Queensland has really been turning on the heat this year so we've put together some basic tips on staying cool, as well as some facts about how heat can impact MS. For those who live with this every day, you don't need to be told how heat affects your MS but perhaps these facts can be shared with family, friends, colleagues who may not understand the impact of heat on MS. It's also worth noting that some people living with MS are just as affected by the cooler weather, but it's summer so we're going to focus on the heat in this article.

The Facts

- An increase in core body temperature affects the nerves' ability to conduct messages so an increase in temperature can mean the messages simply aren't getting through or they're getting through much slower.
- An increase in body temperature by just 0.5 degrees Celsius can cause a worsening of MS symptoms.
- For many people living with MS, heat most significantly affects their fatigue levels.
- Some people also experience weakness, numbness, tingling, blurred vision, confusion/brain fog or a worsening of these when they're hot. Some people also experience fainting.

Tips for Staying Cool

An important thing to remember when trying to stay cool is that heat comes from both external and internal sources. Internal being your core body temperature which can be affected by infections (i.e. flu/fever) and some medicines amongst other things. External being the obvious things like the sun, humid weather etc.

- Listen to your body learn to read the signs that your body is in stress and make the necessary adjustments.
- Plan your exercise.

And finally! Don't be afraid to tell your friends how heat affects your MS. Ask them to consider the time of day that they book social outings (morning catch ups may be preferred) or choosing venues with air-conditioning and asking for a table in the cool.

We'll be posting this article on our website so why not share it on your socials and help raise awareness of the impact of heat on MS. Also keep an eye out for our posts about Heat and MS on our Facebook page.

You can't solve MS, but you can help me remember I'm still the same me by being the same you.

FAREWELL HELEN DELL

In 2019, we farewelled Helen Dell who was part of the fabric of the Redlands MS Support Group and long-standing member of the MS community. We asked some of those closest to Helen to share some words with us.

Helen was the social organiser of the Redlands Support Group and she was lovely with people, but she always avoided coming down the front of the group and would instead ask someone else to talk. She preferred to be behind the scenes for the Group.

Helen was always good at making sure others were okay. She would check in and make sure people were coming to the meeting. She had a knack for making people feel special. She had a lovely sense of humour, she was always the life of the party... she might break into song and even dance a few steps.

She adored her family and would also keep in touch with her extended family. She also deeply cared about people in the Support Group.

Helen was upfront, honest and provided great advice which was always appreciated. She always had a smile on her face. She just made you feel like you were the only person she was speaking to.

John Pesch, Redlands MS Support Group

Helen was and still is an inspiration to all, her courage, love and happiness will remain in the hearts of everyone who met her forever. Before MS took up so much of her life Helen was a keen swimmer and was once in training for the Olympics, however she enjoyed partying more. Helen was a party girl who loved life and people.

She always saw the positive side of a situation and encouraged all to do the same. She was a powerhouse full of love and had an unceasing flow of love. She was a loving, caring and beautiful wife, mother and friend. Laura, Sarah and I were blessed to share our lives with her.

Helen never gave up. She had an unbelievable strength, she would share some of her burden with friends, but like an iceberg they only saw a small percentage of the real issues... WHY? Because she didn't want to burden them. Laura and Sarah saw a lot more of the iceberg, but once again she held things back to protect them. Helen loved both girls with all her heart and they returned that love equally. It makes me happy and sad to say that I saw more than anyone else, but even I was protected from the real depths of her issues.

Her motto was "Never Give Up" the girls and I won't and nor should you. I loved Helen and she loved me. I was in her corner the whole time with her fight with MS and I was with her when she peacefully drifted off to join the other angels.

Peter Dell, Husband



Helen Dell with her Family





Trek Nepal to

BEATMS

Join the Trek Nepal to Beat MS charity challenge in March 2021 and do something extraordinary!



Find out more

WELCOME TO MY WORLD

My body is malfunctioning because of my disease, multiple sclerosis causes problems that displease.

My thermostat's broken, my arms have shrunk, My forgetory's made my brain act like it's drunk.

I once was Superwoman, but sadly am no more, I'm still forever hopeful that they will find a cure.

But it's no fun complaining, I like to have a laugh, My glass is never empty, it's full more than half.

It started with my balance, causing me to fall, A walking stick was purchased begin the list of all.

Two scooters, one named "Mandy", the other "Frankenstein", Wheelchairs, far too many, all helped with a little wine.

"Miss Daisy" helps me roam, and get out and about, When I have somewhere to be or just need some time out.

We go out for meals and sometimes to shows, sometimes to the beach, she just goes with the flows.

She took me to the wharf when I went overseas, we had an awesome time sailing on the Pacific seas.

The shows were fantastic, cocktails and food delish, of course, it'd be rude not to eat lots of fish.

To the airport we went, two years later, to New Zealand, where I stayed with my brother.

The scenery was superb there was no other word, the thought of never going back is really quite absurd.

Another trip is coming up and who knows where I'll go, but MS will not hold me back, just watch me glow.

- Sharon Millow





TRAVELLING WITH BETH

When were you diagnosed with MS and what were some of your symptoms?

I was diagnosed in 2004. I went blind an in my eye overnight and spent three days trying to rub it out before going to my doctor who referred me to an optomologist who diagnosed MS.

My sight did come back after 6-8 months and apart from some 'snow' in my other eye for a couple of weeks. I had no other symptoms for a few years until my left leg started to become weaker and sore ankles etc.

I had also been tired for a while but had been able to push through that, in my head, putting it down to lots of work which is true.

How has your life changed since your diagnosis?

I still work full time. I am a Uniting Church minister and have a passion for helping children, youth and families grow in faith. The MS is a pest. I try to ignore the tiredness/fatigue and sore legs and ankles, but that is getting harder to do. The biggest change is that I have to manage my physical ability.

I find it difficult to stand for a long time, so sometimes I lead a seminar or conduct a church service using my stool that travels with me.

Fortunately, I can do most things sitting down and do a lot of driving in my work. I am blessed that others; family, friends, leaders, and colleagues even youth group kids, who help and accommodate my 'gumby legs'.

We've heard more and more from our community about their travels. Do you have any travel tips?

Getting the Luggie (compact wheelchair) has certainly made my life easier. I hadn't been to a shopping centre for a couple of years, except for "dashing" into a shop that was close to the shopping centre entrance. My husband George has been the household shopper for a few years now.



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I can go shopping by myself now!!!!!!

YEAH!!!! The Luggie has given me back my freedom to go where I like. I have to admit that sometimes it feels like I'm snow skiing like I used to – it's got the gliding feeling like I'm wooshing down a hill on a good run. Of course I try not to go at an inappropriately fast rate.

How did you find out about the Luggie as an option?

When I got NDIS funding my OT went through the options for a mobility device. I went and tried out a few, and decided that even though I am 180cm tall, the Luggie would be the best option. Mainly because of its portability. I needed something that could travel, go to conferences, camps, shops and that I could manage by myself.

Where has your Luggie taken you?

Within weeks of getting my Luggie last May, George and I were off to the UK landing at Heathrow and catching a train and ferry to Ireland. We had a couple of weeks in Ireland doing a bus trip and driving ourselves around.

I organised with Trafalgar Tours to take my Luggie on the tour. I had to fill out all the required paperwork, send specification, photos etc and assure the operators that when folded the Luggie was the size of an average suitcase.

We would get off the bus last and go and get the Luggy, put it up and away we would go..... seeing some amazing sights.

The other thing that happened during the tour was that a manager from Trafalgar tours rang the tour leader to ask how the Luggie was going with the bus. She said 'It's no trouble - we are having a good time!' Hopefully it will give opportunity for others to go on tours!

In August last year, I had a conference to attend at Alice Springs. George and I planned some holidays around that and went to Uluru. It had always been a dream of mine to Segway around Uluru, (we have Segwayed all over the world) but I couldn't stand for the two and half hour Segway tour. So I Luggied it around instead! To be able to go by myself, to stop and look at birds or lizards, or just to listen to the rock was a wonderful and at times a spiritual experience!

What are your travel goals for the future?

This year I'm off to a couple of conferences by myself in Adelaide and Perth. I'll take my Luggie. There will be friends and colleagues who can help if I need it.

In September we are going to San Francisco to go on a cruise to Alaska and then have a week travelling around. I think the Luggie will work well on the boat.

Is there anything you'd like to tell others living with MS?

I know sometimes it is not easy to get around. It takes courage and a smile that will give you more confidence than you feel. I have found that people are kind and willing to help, if we are willing to have a go. It may take planning, and sometimes determination to make it work, but it will always be worth the effort. Get a travel buddy and go and see the world...... start with your neighbourhood and as you gain confidence you will be surprised what you can do.

Thanks for reading my story!







FINDING QUALITY OF LIFE WITH INCONTINENCE

'I continued to have a lot of problems with urinary frequency and nocturia. Last year was a particularly stressful year for me. Thanks to Irene, I now have a better quality of life and control of symptoms.'

J.F., who has decided to remain anonymous, shares her story with us on incontinence and working with Coloplast.

I was diagnosed with relapsing-remitting MS in 1995. Amongst the varied symptoms, bladder and bowel dysfunction was a constant and annoying feature. I live in a rural area west of Brisbane. Just to get from home to Ipswich I knew where there were 7 public toilets. I probably know most public toilets in a 70km radius!

After over a decade, fatigue and urinary tract infections still persisted. Last year was a particularly stressful year for me. I ended up in hospital with an acute kidney infection and not long after that with Influenza A.

After these events, I fortunately met Sarah at Spark Neurocare in Ipswich. She assisted me with my application to the NDIS, as well as introducing me to Irene, the [Coloplast] continence nurse.

Irene is warm and caring, and very easy to talk to, as well as being super-efficient and professional. The telephone receptionists at

Coloplast were most accommodating and helpful - excellent service and follow up. Thanks to Irene, I now have a better quality of life and control of symptoms. Having a steady supply of catheters, no more wash and reuse, is such a bonus. So, for anyone with continence issues, I highly recommend Irene

at MS Queensland and Spark Neurocare. - J.F.



YOU DON'T HAVE TO DEAL WITH INCONTINENCE ALONE - GET IN TOUCH FOR A FREE REVIEW TODAY

To book your FREE review at our Lutwyche, Capalaba, Ipswich, Toowoomba or Virtual Clinic, call us on 1800 316 649 or email nursingsupportau@coloplast.com to secure the next available date.

We can provide the following services:

- Teaching and training in the use of intermittent catheters (for bladder emptying issues)
- Teaching and training of Peristeen transanal irrigation (for bowel incontinence and constipation)
- Product demonstration and sampling (intermittent catheters, bags and sheaths/ condom drainage). Coloplast does not offer a continence solution with pads or absorbent undergarments
- Health and lifestyle education (prevention and management of infections; maintaining bladder health and routine when working/ travelling/ engaging in leisure activity)
- Pre-planning/ review support for NDIS participants using intermittent catheters, indwelling devices, sheaths, drainage bags or bowel products. Coloplast is unable to assist with reviews of pad usage.
- Suitable product recommendations



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Have questions about your catheterising routine? My Continence Check can help identify any issues and when to seek help. Take the Check today!

https://www.coloplast.com.au/about-us/landingpages/my-continence-check/





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