

Rehabilitation, Ageing and Independent Living (RAIL) Research Centre

Friends of RAIL eBulletin #3 - August 2023

Friends of RAIL are people in our community who may contribute to – or use – any of RAIL’s research outputs across the areas of rehabilitation, ageing and/or independent living. Friends include consumer and community members, such as people with their own lived experience across the areas of rehabilitation, ageing and/or independent living, and their families and friends. To become a Friend of RAIL, email spahc.rail@monash.edu.

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**A message from Aislinn
(RAIL Consumer and Community Engagement Lead)**

Hello Everyone,

Welcome to our new Friends of RAIL as we continue to grow – and many thanks to those continuing to share Friends of RAIL so we can develop our network.

This eBulletin highlights a number of Friends of RAIL – with promotion of “pester power” from Grainne, a beautiful poem from Stella, and a spotlight on Coral! As always, we hope you enjoy reading about our activities and outcomes in this eBulletin and welcome hearing from you about what you would like to see or read more about within our eBulletins - or any contributions you consider of interest to others.

Many thanks,

Aislinn

**A message from Grainne
(Friends of RAIL Consumer and Community Representative)**



Welcome to the third Friends of RAIL eBulletin!

In this eBulletin, I wanted to briefly share one of the qualities that helped get Peter and I through the 32 years of living with a traumatic brain injury: *Perseverance (and Pester Power)*.

They say the squeaky wheel gets the oil and I believe it does. We were always fair, so we believed that if there was a need for something to be done we worked for it. Peter lived in an independent living home alongside the train line in Macleod. To go to the nearest shopping centre Peter had to cross the railway line in his electric wheelchair. The asphalt that lined each side of the railway track kept breaking away so Peter's power chair would get stuck down beside the track. While we educated the carers on how to get him out if this happened, we also lobbied the Victorian Railways to have a product called STRAIL (used successfully elsewhere) put on either side of the train track. Peter and his passionate carer/advocate found out about it and never gave up.

The lobbying went over an 18-month period, and eventually the Macleod Railway station was upgraded. Peter's perseverance not only got the STRAIL on both sides of the tracks, but the whole station was overhauled - new or updated ramps, amenities, fencing, gardening, and signage.

As you can imagine Peter was thrilled and this improved conditions for so many, not only wheelchair users but also older residents and parents with prams.

Peter's belief and perseverance won out, he never gave up. We referred to it as "Pester Power"!

Grainne Cruickshank



[Image description: a) Peter at the railway track, next to the construction fence with a 'works are being carried out to improve access for people with disabilities' sign; b) Peter crossing the railway track with the STRAIL installed]

Telling others about becoming a Friend of RAIL



Do you know someone who may like to become a 'Friend of RAIL'? If so, please share [this link](#) with them to complete the registration survey or they can email spahc.rail@monash.edu or call 03 9904 4557 to speak to Karine about registering.

In addition to this Friends of RAIL eBulletin (distributed each quarter), RAIL also runs free networking events for our Friends and invites Friends to contribute to and/or collaborate on education and research activities.

Poem from a Friend of RAIL



[Image description: a) Ms Stella Carew, invited speaker and Friend of RAIL, reading her poem during the 2022 RAIL Rehabilitation Forum alongside A/Prof Libby Callaway and A/Prof Natasha Brusco; b) Two persons, Ms Stella Carew and A/Prof Libby Callaway, side by side facing the camera smiling]

At the end of last year, RAIL hosted a Rehabilitation Forum on the Monash University Peninsula Campus with national and international invited speakers. During the event, we heard a beautiful poem written by one of our invited speakers and Friends of RAIL, Ms Stella Carew. Stella has kindly agreed to share her poem below.

Thank you Stella for your ongoing support to RAIL!

I am swimming

by Stella Carew

I am swimming
Swimming inside my head that is
Oh people send me lifeboats
You should do this, you should do that
You should be this, you should be that
But, the lifeboats were full of holes
And I didn't want to get caught up with them when they sank
So I stayed here, stayed out here alone, swimming in my head
I have M-S you see
That is I have M-S, I am not the M-S
So please see me and not the disease
I haven't done too badly up till now, out here on my own, swimming in my head
So I shall continue down this path
But, not today, today I can surf the waves
I am alive, and I am swimming!

Friends of RAIL network launch event - Save the date!



The RAIL team is planning a launch event for the Friends of RAIL network:

When: Thursday 2nd November 2023

Time: 11:00am – 2:30pm

Where: The event will be held at a venue in the Mornington Peninsula area. More details to come!

What: It will include some brief presentations as well as opportunities for networking. More information will be circulated shortly.

Please save the date! – we would love to see you there!

RAIL Team member introduction

In this edition, we would like to introduce you to the Independent Living Stream Lead **Associate Professor Libby Callaway**:



[Image description: Two persons - Libby and her Mum – sitting side by side wearing Richmond Tigers scarves at the footy]

Hi everyone,

I am an occupational therapist, researcher, and the Independent Living Stream Lead at RAIL - this stream focuses on research with people with lived experience of disability or other complex health conditions. My interest in the field of disability started whilst studying my occupational therapy undergraduate degree in the early 1990s, when I worked as a disability support worker with people with lived experience of acquired brain injury and their families. This role included working with Grainne Cruickshank (Friends of RAIL Consumer and Community Representative) and her wonderful husband Peter.

I have around 30 years of clinical experience (mainly within acute hospitals, rehabilitation settings, and community based private practice) and 15 years of research experience. After working in both Australia and the USA, in the late 1990s, I started a community based [private occupational therapy practice](#) for people with neurological disability, called Neuroskills, which I still run to this day. In 2006, I joined Monash University and I now work across the Occupational Therapy Department and the RAIL Research Centre. My research has grown over the years to focus on various factors that can impact outcomes and experiences of people living with disability and their families - including housing, assistive technology, and both the human and animal supports (like assistance animals) they may draw upon. I also do project work at Monash to demonstrate different ways of developing products and services to meet the goals and needs of people with disability and their families - one of those is [smart technology enabled independent living units](#) we developed on the border of Monash Peninsula Campus, which opened in 2015 and are now funded by the [National Disability Insurance Scheme](#).

If you would like to know more about our team or the Centre itself, please visit <https://www.monash.edu/medicine/spahc/rail/>

Spotlight on a Friend of RAIL

Coral Keren

I graduated as a Physiotherapist from Melbourne University. I have worked at the Alfred Hospital and Fairfield Hospitals and then in private practice. I have also worked as a Physiotherapist in Geneva, Switzerland, and Chicago, USA. I was fortunate to work at the Rehabilitation Institute of Chicago (now called Shirley Ryan Ability Lab). This is an amazing hospital which integrates research, teaching and treatment. It is on the cutting edge of rehabilitation and I learned so much there. *[Image description: Headshot of a person, Coral Keren, smiling at the camera]*



After my husband and I retired we moved back to Melbourne. I have been active as a Consumer Representative on many boards including Cabrini Hospital and Monash Health. This is where I met Keith (Director of the RAIL Research Centre) and he invited me to join RAIL.

Having been "on both sides of the sheets" as a health care worker and a patient, as well as helping other family through the health care system, both here and in the US, I feel I have a lot to offer.

The system in Australia is good but there is always room for improvement.

I look forward to being a part of RAIL which I feel has so much potential to benefit lives and make a difference.

My husband and I love to travel and now with Covid less of an issue we are back on the road again.

If you would be happy to provide a Spotlight of yourself to be featured in upcoming Friends of RAIL ebulletins, please contact Karine via emailing spahc.rail@monash.edu or calling (03) 9904 4557.

Top Tip from the RAIL team

Top Tips



Would you like to get tips and/or increase your skills in using digital space? Check out these two programs:



1. *Victorian Tech Savvy Seniors* is a Seniors Card Age Friendly Partners Program available in Victoria designed to make day-to-day services more age-friendly. You can join the Telstra Social Seniors program at your local library to learn basic skills to keep in touch with family and friends online:
<https://www.seniorsonline.vic.gov.au/get-involved/victorian-tech-savvy-seniors>
2. *Be Connected* is an Australian Government initiative aimed at increasing the confidence, skills and online safety of older Australians in using digital technology. To know more about the *Be Connected* program, please visit:
<https://www.dss.gov.au/seniors/be-connected-improving-digital-literacy-for-older-australians> and <https://beconnected.esafety.gov.au/>

If you have a top tip that would like to share with others, please feel free to contact us at spahc.rail@monash.edu.

Reflection from the recent Friends of RAIL morning tea



[Image description: Images show various viewpoints of the RAIL team presenting and engaging with Friends of RAIL, as well as our 4-legged attendee 'Wag' - a blonde Labrador guide dog in training.]

RAIL was pleased to host its first "Friends of RAIL" morning tea event on the Monash University Peninsula Campus on Thursday 1st June 2023.

The event was a great opportunity to meet and hear from Friends of RAIL on how RAIL:

- should and could engage and collaborate with the network;
- how to best listen and work with our Friends across every stage of a research project to ensure RAIL's work is truly co-designed; and,
- how we can ensure we provide accessible and inclusive knowledge sharing.

If you know someone in the community who would like to be linked in with our Friends, please share the link to our [Friends of RAIL registration form](#) or alternatively ask them to contact us at spahc.rail@monash.edu.

Research participants required

Are you a person aged 65 years or older who has been diagnosed with hip or knee osteoarthritis?

Monash Uni researchers are looking for people to participate in a **six month program** for people with osteoarthritis that aims to **keep them active, improve their balance and prevent falls.**



MONASH University

Monash University Human
Research Ethics Committee
(ID 23302).

To express interest, and to chat to a member of our research team, **please follow the QR link**, or email Sze-Ee at **sze-ee.soh@monash.edu**

Are you a person aged 65 years or older who has been diagnosed with hip or knee osteoarthritis? Do you know someone who is aged 65 years or older who has been diagnosed with hip or knee osteoarthritis?

Falls are a leading cause of injury and hospitalisation among older people. While effective falls prevention programs do exist, falls prevention has not traditionally been a common component of osteoarthritis care.

Monash University researchers are seeking your help with a new research into osteoarthritis and falls prevention aiming to develop and test a falls prevention program that is tailored to people with osteoarthritis.

This research, funded by the Rehabilitation, Ageing and Independent Living (RAIL) Research Centre at Monash University, has been approved by the Monash University Human Research Ethics Committee (ID 23302).

To express an interest in participating in this research, please contact Chief Investigator Dr Sze-Ee Soh, School of Primary and Allied Health Care on 03 9904 4122, or Sze-Ee.Soh@monash.edu, follow the QR code in the poster above or click on [this link](#).

Publications and Resources that may be of interest

Inclusion Australia Circular

[Inclusion Australia](#) have recently launched a new Easy Read newsletter to help people in the disability community find out about opportunities to be involved in research and consultation. You can find out more about their newsletter and access the latest edition by visiting: <https://www.inclusionaustralia.org.au/have-your-say-in-research-projects/>

Compass website by Elder Abuse Action Australia (EAAA)

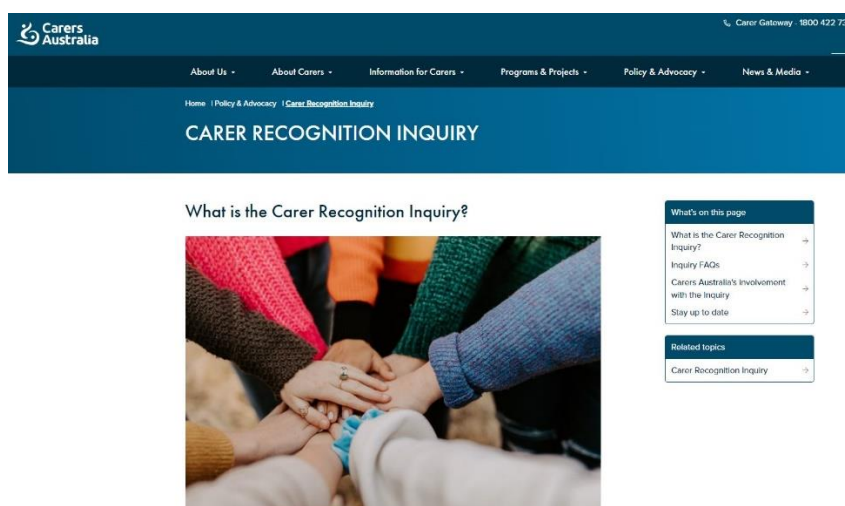
Recently Libby (Independent Living Stream Lead of the RAIL Research Centre, highlighted in this eBulletin edition) had the pleasure of speaking with the Hon Kay Patterson, Aged Discrimination Commissioner at the Australian Human Rights Commission, who flagged a useful web-based resource, *Compass*, that you may also be interested in.

'Compass is a national website navigating elder abuse in Australia that has been created by Elder Abuse Action Australia (EAAA), with funding from the Australian Government Attorney-General's Department. It aims to create a national focus on elder abuse by raising awareness of this growing social issue, and simplify the process of connecting people to services and information tackling elder abuse.'

This web-based resource includes [lived experience stories](#) that may be of interest.

To know more about compass, please visit: <https://www.compass.info/>

Inquiry into the recognition of unpaid carers



The Australian Government recently announced an "Inquiry into the recognition of unpaid carers". 'The inquiry is looking into the provisions and operation of the Carer Recognition Act 2010 (the Act) in relation to unpaid carers, with a view to reform through legislative amendment.'

The Committee in charge of this inquiry is now requesting input from individual carers, carer representatives, and advocacy organisations (**deadline: by Friday, 11 August 2023**).

To know more about this inquiry and how to provide input, please visit:

<https://www.carersaustralia.com.au/policy-advocacy/carers-recognition-inquiry-2/>

Friend Contribution and Feedback

At RAIL, we are committed to conducting research that occurs with the community and would love to hear from you. If you would like to share a story related to your experience of rehabilitation, ageing and independent living, be involved with RAIL research, share a top tip with Friends of RAIL or provide any feedback that you may have on the format/content

of the Friends eBulletin, please contact us at spahc.rail@monash.edu or call 03 9904 4557.

RAIL aims to provide an accessible ebulletin for all. Image descriptions are available for images appearing in the ebulletin, with the use of a screen reader. If you have any issues with accessing any part of the ebulletin, please let us know at spahc.rail@monash.edu.

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<https://www.monash.edu/medicine/spahc/rail/>

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spahc.rail@monash.edu

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