

Rehabilitation, Ageing and Independent Living (RAIL) Research Centre

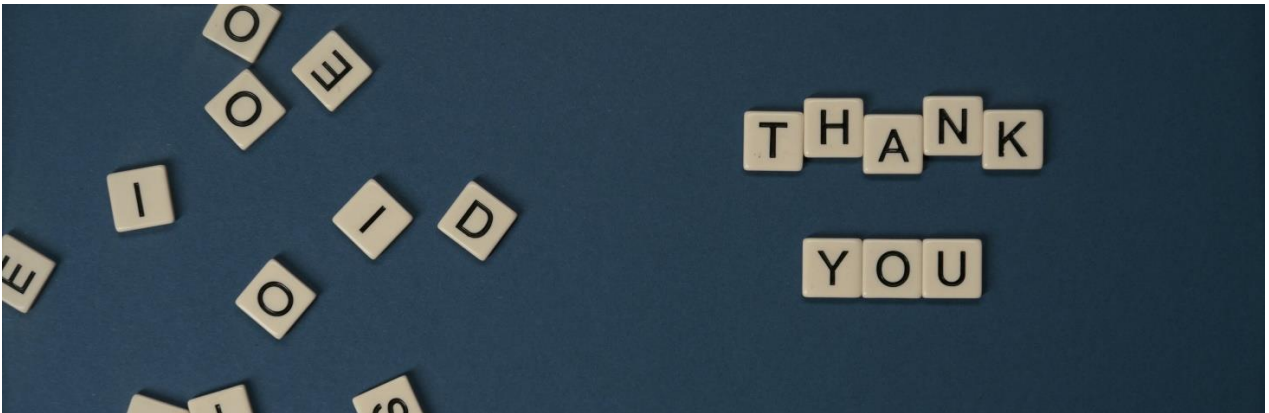
Friends of RAIL eBulletin #4 - December 2023

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.

In this RAIL Friends eBulletin edition:

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



Hello Friends,

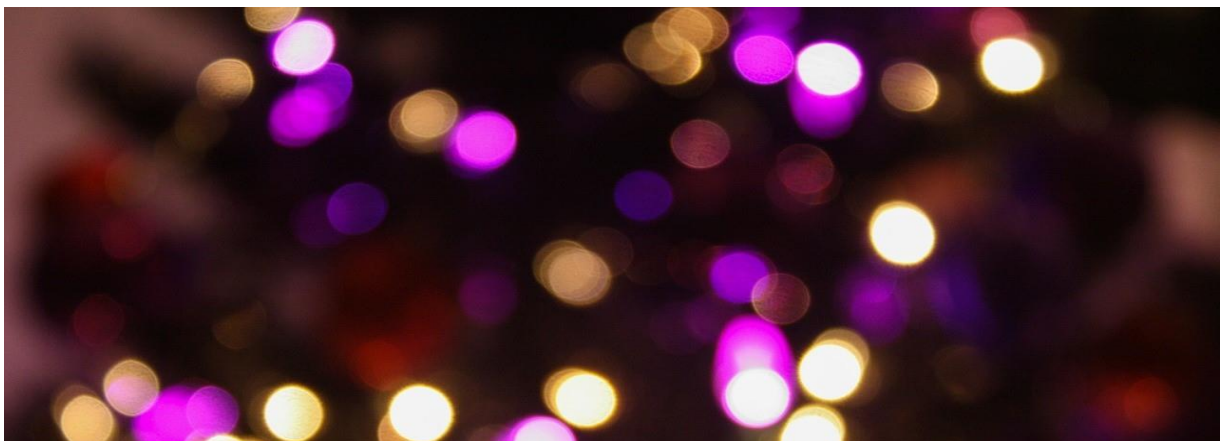
Hope this final Friends eBulletin finds you all in readiness for the upcoming festive season and holiday break. Firstly, I would love to thank all our Friends who were able to attend our recent Launch of Friends of RAIL (more details later in this eBulletin) – it was a fantastic opportunity to gather and engage with you all, with particular thanks to Vince, Coral and Chris for providing additional input prior to the day to initiate discussion on the day!

This bulletin also includes a lovely update from our “Head Friend”, Grainne, a couple of spotlights – one of Angel Lee (a Research Fellow at RAIL) and one of Margaret (Friend of RAIL), as well as some project spotlights and our usual Top Tip that hopefully you will find helpful. As always, if you’d like to provide us with any feedback, or contribute to our e-Bulletins, please feel free to do so (details at the bottom of this eBulletin).

Wishing you all well for the holiday break and a happy new year – and look forward to being in touch in 2024.

Many thanks,
Aislinn

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



Hi everyone and welcome to our last 2023 edition of the Friends eBulletin, also welcome to our new Friends, it was nice to meet some of you at the launch of Friends of RAIL.

As some of you know, my name is Grainne (pronounced Gron-ya) and I am the Friends of RAIL Consumer and Community Representative.

I have lived rehabilitation for 30 plus years. My husband Peter had a significant brain injury from a motor car accident 2 years into our marriage, but we were lucky to have another 32 years together living life. I also lived with my father until he was 89 and sadly needed more care than we were able to give him.

Lately, I have been asked about assistive technology (AT) that helped Peter. Of course, Peter had extreme amounts of assistive technology aids to his everyday life. Of the low-cost AT, one of the standouts (possibly because it could have been the cheapest) was a straw holder!

It is hard to explain but hopefully the picture helps. It clipped onto the side of any glass and the straw slid into it. Peter only used his left hand so when he had a drink he would chase the straw around the glass, extremely frustrating. This little straw holder that I don't even think cost \$1 gave Peter back some independence. Thank you to the manufacturers, therapists, and friends who identify and research needs.



Of course I would love to talk more about some of the other assistive technologies Peter and I used possibly in future eBulletins. If you've any AT tips you'd like to share, please feel free to do so (see details about how to do this towards the end of this eBulletin).

Grainne Cruickshank

Telling others about becoming a Friend of RAIL



Do you know someone who may like to become a 'Friend of RAIL'?

If so, please either:

- 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.

RAIL Team member introduction



Dr. Den-Ching Angel Lee works at Monash University as a Research Fellow in the National Centre for Healthy Ageing and the Rehabilitation, Ageing, and Independent Living Research Centre. She is a registered physiotherapist and focuses on research to promote healthy ageing. Her main goal is to improve the well-being of older individuals, especially those with dementia, and their caregivers to enhance their overall quality of life.

In her research, Angel collaborates with stakeholders and consumers, incorporating their input at all stages (using co-design principles). She strongly believes in developing these solutions in collaboration with the people they are meant to benefit. Her work also involves evaluating how well these co-designed solutions work and assessing the implementation process.

Angel's research covers various topics, including tailored physical activity programs for people with dementia, with a specific focus on those from culturally and linguistically diverse backgrounds. She also addresses the prevention of accidental falls of older adults, mobility care for individuals with dementia, rehabilitation for people with dementia, and reducing restrictive care practices in aged care and mental health settings. She is dedicated to promoting evidence-based practices among healthcare professionals.

Working and collaborating with aged care providers, Angel explores innovative strategies to improve the quality of aged care services. She also empowers the aged care workforce to actively participate in reablement services, ultimately contributing to the well-being of older individuals and their caregivers.

Spotlight on a Friend of RAIL

Hi Everyone,

My name is Margaret Thomas and earlier this year I reached the grand old age of 80 years. This gave me an opportunity to review my life's achievements, and reflect on what I would have done differently if I had my time over again.

My schooling was cut short because I was a girl. I would marry and not need to be tertiary educated. My parents thought their son should be educated, rather than their daughters. How wrong they were. I did redress my education gap by attending university and achieving a Post Graduate Degree in Health Promotion at the grand old age of 60.

I would never have done this if I had not worked with the Victorian Department of Human Services. I had joined the Department after participating in the Task Force into Dementia Services in Victoria.

The Task Force gave me the opportunity to get back into the paid workforce. My earlier working life had been in the office equipment industry; I found advocating for people with



dementia and their carers was a new world. The Task Force met for two years which led to a permanent position implementing the strategy based on the recommendations of the Task Force.

Over the next seventeen years I worked in the dementia, acquired brain injury, and falls prevention portfolios. This was influenced by my personal caring experience of looking after my late husband. During the fifteen years I cared for him I learned a lot about myself and the challenging, and little-understood role of carer. I had the ambiguous role of being neither a “wife” nor a “widow”.

Apart from my family, my passion in life is encouraging everyone to participate in exercise. My parents had encouraged me to engage in gymnastics, tennis, swimming, running and team sports like softball and basketball.

Meeting a mad keen golfer in 1964 I switched to golf for the next 20 years before our family dynamics changed and I found becoming a mother and the restraints of not having a regular babysitter introduced me to aerobics and yoga. These days water aerobics and gardening are my preferred exercises as they don't stress my body quite as much as Pilates and yoga.

Early in 2020 I was introduced to RAIL through Professor Keith Hill by joining the External Advisory Committee for RAIL Research Monash University as a consumer representative.

Projects I've contributed to include:

- Physical activity for people with mild dementia
- Gait aids for people with dementia
- Dementia Home Care Exercise Project

Also:

- Monash Partners workshop during COVID in 2022: Falls prevention in hospital settings, and
- RAIL's one-day seminar: Exercise to optimize balance, mobility and fall outcomes for older people.

The opportunity to participate in this amazing work contributes to my health and well-being. Promoting better general physical and mental health continues to be my mantra in life. Overcoming the inertia many people have about making exercise a part of their daily routine is not an option if you want to live a long and meaningful life.

Becoming a Friend of RAIL is the first step anyone can take to learn about what is happening in research, and what opportunities there are to widen your horizon and make the most of your life.

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.

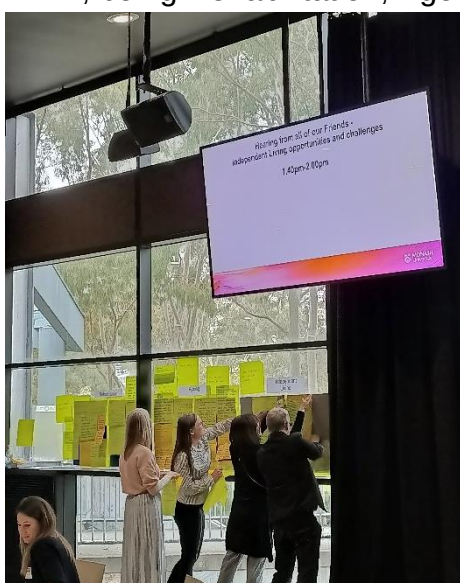
Reflection from the recent Launch of Friends of RAIL



[Image description: Friends of RAIL event with Aislinn and Grainne presenting in the top left corner photo; Friends of RAIL and team discussing the challenges and opportunities in rehabilitation, ageing and independent living in the top middle photo; three narrative portraits involving Friends and RAIL team on the top right photo; final group photo at the bottom]

On Thursday 2nd of November, 2023, Professor Terry Haines (Head of the School of Primary and Allied Health Care at Monash University) led our official Launch of the Friends of RAIL.

We were very fortunate to have presentations of key challenges and opportunities identified by Vincent Rovtar, Coral Keren and Chris Le Cerf, across our three streams of RAIL, being Rehabilitation, Ageing and Independent Living. Our three Stream Leads also responded briefly to each of our Friends. Following a lovely lunch where new and existing Friends of RAIL were able to connect, the afternoon session involved interactive group discussions about challenges and opportunities across rehabilitation, ageing and independent living – building on the key points of Vince, Coral and Chris. Each table made notes on large post-it notes and the key points of discussion are currently being typed up and synthesised into a document called a White Paper. This document will help provide a base to which our RAIL team can draw on, but also assist others in identifying some of the challenges and opportunities that are faced by individuals across ageing, disability and independent living, and rehabilitation.



We very much thank all those who were involved on the day and look forward to sharing the final White Paper from this day with you all in 2024.

RAIL Project Spotlight - Ageing well with traumatic brain injury

Australia's population is ageing, and so too are people with injuries. What this means is that on average people are slightly older when they get injured and they are living longer with the impacts of injury. For people with brain injuries this means that they may need more time and support for recovery when they are first injured and that their health care and support needs may change or increase as they age.

To understand these issues better, two injury insurers, the Transport Accident Commission Victoria and icare NSW, have provided funding to Dr Christina Ekegren, Associate Professor Libby Callaway and 'Head Friend' Grainne Cruickshank from RAIL and researchers from the University of Sydney to develop a resource to help people who are ageing with brain injury better manage their health. The resource, 'Ageing well with traumatic brain injury', will also be useful for health professionals who are caring for people with brain injury so they know what to look out for and insurance claim managers so they can tailor their support. We look forward to sharing this resource with our Friends in about 12 months' time.

[Click here to view a 2-min project summary video](#)

Collaborating with the Polio Community

Dr Natasha Layton of RAIL is a longstanding voluntary member of the [Clinical Advisory Group](#) of Polio Australia. Collaborations with polio survivors have taken various forms including research and publications, such as the 2012 [Wait Times Report](#) into the impacts of waiting for assistive technology funding, and joint conference presentations such as the 2012 Research Rights Conference and 2016 International Polio Symposium.

To mark World Polio Day on October 25th this year, Natasha gave a keynote address to around 60 polio survivors in Hastings, Victoria. The requested topic, **What have Human Rights got to do with Assistive Technology**, generated a lot of discussion about the progressive realisation of rights and the changing policy and funding context over a lifetime for people with polio.

Post Polio Victoria (PPV) has won first prize in the Focus on Ability™ annual International Short Film Festival challenges filmmakers to create a short film that celebrates the achievements and abilities of people with disability.



[Image description: Assistant Director with the Australian Department of Health, Dion Abel, Dr Natasha Layton (RAIL Research Centre) and Hastings MP Paul Mercurio]

[Click here to view the Post Polio Victoria 5-min documentary](#)

Top Tip from the RAIL team

Top Tips



Making Choices, Finding Solutions



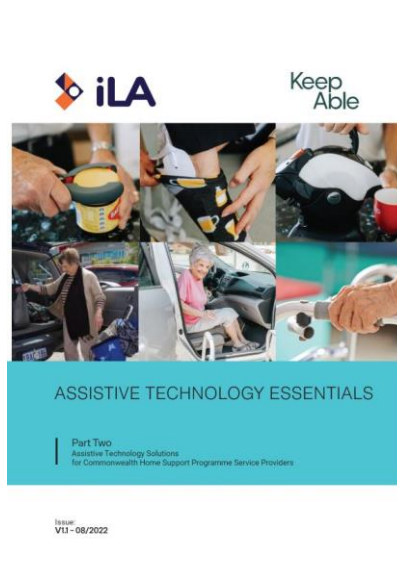
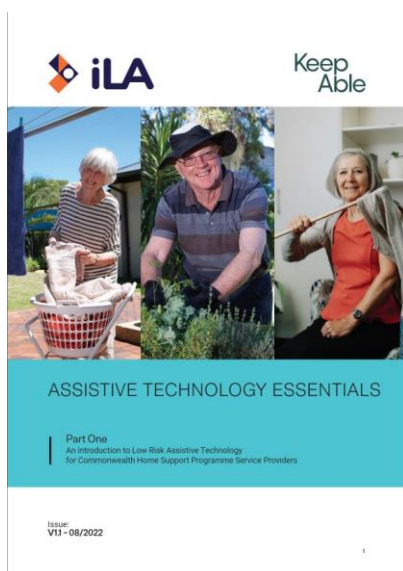
Living the lives of our choosing can be a challenge in the face of functioning limitations. Changing the way tasks are done, introducing energy conservation strategies and joint protection techniques, adjusting the environment and introducing daily living equipment (assistive technology) can make a difference.

The Making Choices, Finding Solutions e-book draws together advice for daily living from experts by experience and from rehabilitation professionals.

Making Choices, Finding Solutions 'eBook':

https://issuu.com/ila-inc/docs/new_2022_mcf?fr=xKAE9_zU1NQ

Focussing in on assistive technology, the comprehensive AT Essentials eBooks provide a visual guide to what's available for daily living:



AT Essentials Pt1 'eBook' https://issuu.com/ila-inc/docs/intro_to_low_risk_pt1.1?fr=xKAE9_zU1NQ

AT Essentials Pt2 'eBook' https://issuu.com/ila-inc/docs/assistive_technology_essentials_pt2?fr=xKAE9_zU1NQ

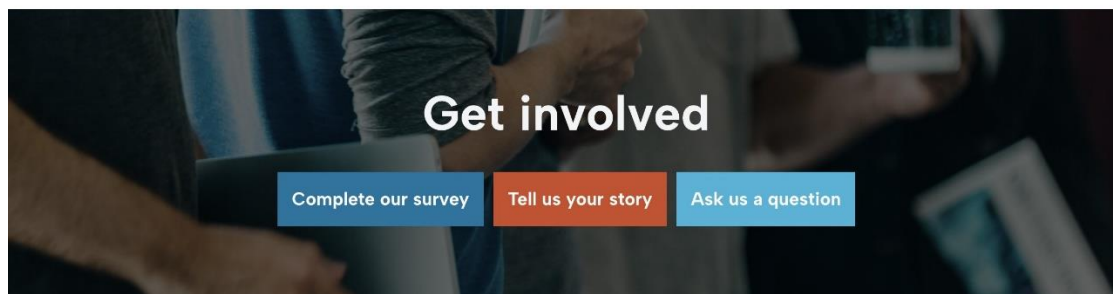
If you have a top tip that would like to share with others, please feel free to contact us at spahc.rail@monash.edu.

Workers' Voice on ABC Conversation Hour

The Chief Investigator of a new ARC Discovery Grant Project, Professor Alex Collie, was joined by the Friends of RAIL Consumer and Community Representative, Grainne

Cruikshank, and two other people with lived experience of Workers' Compensation Schemes on the ABC Conversation Hour with Richelle Hunt last week. To listen to this contribution on demand, go to: <https://www.abc.net.au/listen/programs/theconversationhour/the-conversation-hour/103118214> To learn more about the ARC Discovery Grant Project, called Workers' Voice, you can read [this article](#) or visit the project website via <https://workersvoice.com.au/>

People with lived experience of workers' compensation, or their families or friends, may wish to share their perspectives on Workers' Compensation via a brief survey on the Workers' Voice website, which can be accessed via <https://workersvoice.com.au/workers-voice-survey/> There is also the option to nominate to share your Workers' Compensation story - for details, go to <https://workersvoice.com.au/tell-us-your-story/> People can also ask questions of the research group via <https://workersvoice.com.au/ask-us-a-question/>



Workers' compensation from a lived experience perspective

Workers' Voice is a research study that aims to re-imagine workers' compensation in Australia.

This 3-year study recognises that there is opportunity to improve the management and design of workers' compensation systems so that they can better support workers who have been injured to return to work following a workplace injury or disease.

Publications and Resources that may be of interest

Be My Eyes

Do you know someone with low vision or blindness? Are there times when they may benefit from someone to 'be their eyes' - for example, when travelling on holidays and wanting to use the microwave in a hotel, which has a different interface to someone's own microwave at home or when shopping alone and wanting to check whether the colour of a jacket matches with their pants?

Be My Eyes is a 24/7 global online community that connects people with low vision or blindness with sighted volunteers using video calls, with the volunteer 'lending their eyesight for everyday tasks'.

To learn more about Be My Eyes and how people are using or volunteering in the program, go to: <https://support.bemyeyes.com/hc/en-us/articles/360005528557-Getting-Started-with-Be-My-Eyes>

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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