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REHABILITATION, AGEING AND INDEPENDENT LIVING (RAIL) RESEARCH CENTRE

Friends of RAIL eBulletin 1 - February 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 Keith (Director of RAIL), and Aislinn (RAIL Consumer and Community Engagement Lead)

Hi everyone, and welcome to 2023, and the first e-bulletin for Friends of the Rehabilitation Ageing and Independent Living (RAIL) Research Centre at Monash University. It is very pleasing to see the formal launch of the Friends of RAIL, as a critical group to support, inform and guide in varied ways the research agenda, activity and outcomes of our Centre.

RAIL is a fairly new research centre (we commenced operation three and a half years ago in July 2019). We faced the challenges (as everyone did) of the COVID pandemic, which has substantially impacted on some of the activities we had hoped to initiate during this period. Nonetheless, RAIL has now become a successful and growing research centre. We have achieved some important research outcomes, and have a number of current and completed studies across the areas of rehabilitation, ageing and independent living.

Below is one example of a Senior Exercise Park at Thomas Street in Hampton (Victoria). RAIL, in collaboration with the National Ageing Research Institute, have undertaken a series of studies showing the safety, feasibility, acceptability and effectiveness in improving physical and mental health outcomes for older people, and these parks are now increasingly being installed in other community parks.



We hope to use these e-bulletins as one way to keep you informed about what we are doing. We will also give you information on the findings and implications of our (and others') research with the aim to share our work with the wider community. This community includes people with their own lived experience across the areas of rehabilitation, ageing and/or independent living, as well as their families, friends and other key supporters. We hope that being a Friend of RAIL is a valuable two way relationship for you and for the RAIL Research Centre.

There are many ways that you can be involved to work with RAIL towards achieving our goals – these include free education sessions and forums, and contributing to and/or collaborating on education and research activities with RAIL. We also hope to provide opportunities for information sharing of relevant research outcomes, and opportunities for networking between Friends of RAIL. We are keen to hear your ideas on how Friends of RAIL can grow and become a supportive, collaborative and influential group.

We hope you enjoy reading about our activities and outcomes in the eBulletin, and we welcome any contributions you consider will be of interest to others.

Professor Keith Hill and Dr Aislinn Lalor

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

Hi, my name is Grainne (pronounced Gron-ya),

When I was asked to become a member of the RAIL External Advisory Committee 2 years ago I was excited and pleased to be able to be involved. Now to have an involvement in the setting up of the Friends of RAIL I feel is really valuable.

I have lived experience of rehabilitation, ageing and independent living.

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. He lived in Rehabilitation hospitals for ten years of that time and everyday was built on therapy, teaching him the skills that had been lost/altered with his brain injury. He dealt with physiotherapists, occupational therapists, speech therapists every day sometimes twice a day. This was extreme rehabilitation but so, so important. My husband and I travelled extensively both in Australia and overseas being supported by carers and family with wheelchairs and shower chairs in tow.



I was also lucky enough to live with my father for eight years, before he went into an aged care home where he spent his last two years. **Ageing** was hard for dad, with the loss of independence. Having to rely on others sometimes for the smallest of things. Being the one that needs the help or support when he was the one that supported us through all our lives.



My experience of **independent living** was when Peter moved from a hospital environment to a home in a community that was designed and purpose built for

four people with severe brain injuries that all used powered wheelchairs. This was an amazing time in our lives, for Peter to be part of a suburban community, to be part of decision making around a home and his care. Fortunately, Peter and I were strong enough to navigate our way and have a wonderful married life together. Hopefully we educated many on what could be done to make Peter's life the best it could be and support our marriage. We contributed some of this learning previously in a 'Housing Toolkit' published by the Summer Foundation, which you can download [here](#) - our story is on page 99.

I am normally the reader - devouring all the advice on how, when and where - not the writer. So for me, being involved with Friends of RAIL, I am hoping it is a sharing of information and positive experience for us - RAIL's Friends. I look forward to keeping in touch with you all across the year. Please feel free to reach out to me or RAIL via spahc.rail@monash.edu and please also feel free to share this first eBulletin with your family and friends, and encourage others to become a Friend of RAIL.

Many thanks, Grainne

P.S. You can read more about me in the Spotlight on a Friend of RAIL below. Maybe you would like to do a Spotlight on yourself sometime soon? We would love to hear from you.

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.

RAIL also has Members (Monash education and research staff interested in rehabilitation, ageing and independent living) and Partners (external organisations who provide services across these three areas).

RAIL Team introduction

The Rehabilitation, Ageing and Independent Living (RAIL) Research Centre coordinates research and projects to meet Australia's future health and care needs. It is located at the Monash University Peninsula Campus in Frankston, Victoria. The Centre comprises a Director, Stream Leads (for "Rehabilitation", "Ageing", and "Independent Living") and Research Fellows, including:



Prof Keith Hill
Director and ageing lead



A/Prof Libby Callaway
Independent living stream lead



Dr Natasha Brusco
Rehabilitation stream lead



Dr Christina Ekegren
Senior Research Fellow



Karine Fortin
Senior Research Officer



Dr Natasha Layton
Senior Research Fellow



Dr Aislinn Lalor
Senior Research Fellow



Dr Angel Lee
Research Fellow

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

We will provide a brief introduction to the various RAIL team members in each e-bulletin. Below we provide a brief introduction to Dr Aislinn Lalor.



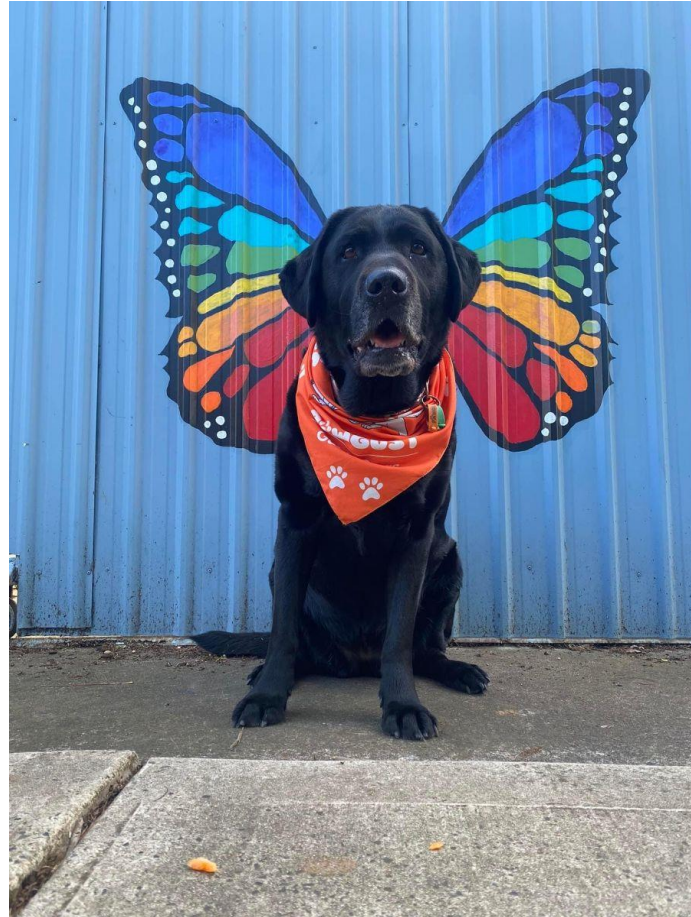
Dr Aislinn Lalor is an Early Career Researcher, Senior Lecturer and Senior Research Fellow at Monash University. Aislinn's occupational therapy background has included teaching at Monash University since 2009, and clinical work in acute aged mental health and community health positions prior to undertaking her PhD regarding sleep quality of older adults in 2013.

Aislinn is currently a part-time Senior Research Fellow with the RAIL Research Centre at Monash University. Aislinn is passionate about healthy ageing and evidence-based translational research. Her current research interests include the co-design and implementation of a Carers' Clinic on the Mornington Peninsula, as well as research in the areas of ageing, sleep, and palliative care.

Aislinn is the Consumer and Community Engagement Lead and will work closely with Grainne in developing Friends of RAIL. Please feel free to contact Aislinn via spahc.rail@monash.edu if you've any suggestions regarding the development or activities of Friends of RAIL. Aislinn is also the Secretary for the Australian Association of Gerontology Victoria Division Executive Committee.

In her spare time, Aislinn volunteers her time with Guide Dogs Victoria; coordinates Guide Dogs Victoria puppy raisers to attend Monash Peninsula Campus each year as part of the national RUOK? Day – for staff and students;

and loves taking long walks with her reclassified Guide Dog, Jazara; sewing & crafty things; travel and dining out with friends.



Top Tips from the RAIL team

Top Tips



In each e-Bulletin we aim to share “top tips” or links to information that may be of interest and relevance to you. Our first top tips are:

- 1) Assistive technology includes both aides and equipment (or assistive products) as well as the services a person use to consider, select and learn how to use a product. Have you checked out the 20,000+ assistive products on the National Equipment Database, ‘Ask Ned’? You can search for a particular product (e.g. long handled shoe horn or shower chair) or category (e.g. kitchen or bathroom aides). To explore this resource, go to <https://askned.com.au/>
- 2) Are you interested in learning more about healthy ageing? Take the Live Up quiz via <https://www.liveup.org.au/> and gain access to a comprehensive list of exercise classes, product suggestions, and local groups.

Spotlight on a Friend of RAIL



Who am I?

My name is Grainne Cruickshank (pronounced Gron-ya), I am based in Melbourne, Victoria. I am mostly retired, although I do have a few voluntary roles. I have previously worked in administration positions in retail, wholesale and service companies, which I loved, as I dealt with the customers in all these roles.

Why/how did you become a friend of RAIL?

I have had 30 plus years of experience of caring for my husband who sustained a significant brain injury two years into our marriage and we were lucky enough to have 32 happy years together. We navigated many systems, dealt with teams of professionals, worked our way through many health conditions, many

housing issues and 32 years of equipment or I now know the correct term is assistive technology! Many, many issues or much experience. My husband passed away 3 years ago and I feel that all my experience may be able to help others.

Any links you have had with RAIL Projects/Staff?

Yes, I have two key links with RAIL. I am currently a member of the External Advisory Committee for RAIL Research Monash University. Through this my lived experience and perspective helps inform the research priorities and opportunities for the RAIL Research Centre and the visibility of the Centre's work across the community. Libby Callaway is the Independent Living stream lead at RAIL and I have known her for many years. Libby was a student OT with my husband when she was studying Occupational Therapy back in the year 1990s.

Life outside RAIL?

I am retired but I lead quite an active life. I have plans to travel mid this year. I have family in Ireland that I am visiting and we will travel together. I have a few voluntary roles which I enjoy being part of including those with RAIL and also with the Australian Rehabilitation and Assistive Technology Association (ARATA - <https://www.arata.org.au/>).

I wish to travel as much as I can so beyond (and during!) my work with RAIL, I travel. Zoom is a wonderful thing - it allows you to be involved from anywhere. I am in the process of moving home, and downsizing! I think I am learning how to cull. Following my move, I look forward to finally having a dog. I have shared many family pets, but I really can't wait for the day I have my own.

Random facts about me?

1. Grainne is Gaelic for Grace.
2. I found out during Covid that I am not bad at doing jigsaws.
3. My laundry is my happy place (certainly not the kitchen).

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

RAIL Project spotlight

Each eBulletin one of the RAIL team members and/or RAIL partners and members will provide a brief summary of a current or completed project. This eBulletin we would like to introduce you to a project in the Ageing stream, called "Is there a role for gait aids to improve stability and reduce falls risk for older people with dementia? (funded by Dementia Australia, lead RAIL researchers: Dr Angel Lee and Professor Keith Hill).

One of the common approaches to improve steadiness when walking and to reduce risk of falls for older people generally is to consider use of a walking aid (eg a stick or a walking frame). However, there is confusion about whether this is appropriate and safe for a person with dementia who is unsteady, or whether it might increase their risk of falling. This study had a number of parts. Main findings were that the majority of people with mild to moderate dementia who participated in a six week training program (four home visits from a physiotherapist, and in between supervision and practice with the carer, if this was considered safe) were able to achieve safe walking with the walking aid. A tip sheet is being finalised to assist carers considering if there might be value in trialling a walking aid for the person with dementia who they provide care for. Having an assessment by a physiotherapist or an occupational therapist would be an important initial step if considering this.



Photo reflection from RAIL



On the 1st December 2022, RAIL held a one-day event for consumers, researchers and clinicians, entitled “Putting the consumer at the heart of rehabilitation”. The focus of the day was to showcase the important role of consumers in improving the quality of clinical care and research in rehabilitation.

Highlights of the day included a moving interview with Dr Annie McCluskey, Occupational Therapist, and Mr Karl Schurr, physiotherapist, who spoke about their personal and professional rehabilitation journey following COVID-19.

There was also an inspiring interview with Ms Britta Morrison, who was involved in a devastating car accident on the Mornington Peninsula in July 2012, and Dr Sandy Reeder, who has made consumer-based research the focus of her work in trauma recovery.

Finally, Ms Stella Carew read her powerful poem “I am Swimming”, reflecting on the importance of understanding lived experience of disability. What was most heartening was the large presence of our RAIL friends, partners and

members in the audience, who also stayed for a social catch up with RAIL staff at the end of the day.

A big thanks to Karine Fortin for her careful and thoughtful planning of the event, Dr Natasha Brusco, RAIL rehabilitation stream lead and Associate Professor, Libby Callaway, RAIL independent living stream lead for their leadership, and all of our presenters, including Professor Keith Hill, Professor Christina Mitchell AO, Ms Sara Whittaker, Dr Christina Ekegren, Professor Nicola Kayes and Mr James Bonnamy.

Upcoming events

RAIL Friends Event

We are planning our first Friends of RAIL event to be held in the Frankston region between June and September 2023. We would love to hear from current Friends as to what you would like this event to include. For example, maybe you would like, brief presentations from each RAIL stream Lead on our research or specific presentations or informal opportunity to network with other Friends? Would you like it in person or online?

You can let us know by emailing spahc.rail@monash.edu or calling (03) 9904 4557.

Publications and resources that may be of interest

Independent Mental Health Advocacy - NDIS Mental Health Toolkit

The NDIS Mental Health Toolkit, written by the Independent Mental Health Advocacy (IMHA), is for people who may be considering applying for, or are already a participant of, the National Disability Insurance Scheme (NDIS):

"The toolkit has information and worksheets to help you know your rights and speak up for yourself, whether you are applying for the National Disability Insurance Scheme (NDIS) or have already been accepted.

We created it with people with experience of using the mental health system and the NDIS. They told us they wanted to know more about how to self-advocate under the NDIS' psychosocial disability stream, and what information and features the toolkit should have.

The toolkit is designed for people with lived experience of the mental health system who use or are eligible for the NDIS, but can also be used by supporters, such as carers, kin, family of origin, family of choice, friends, community members and support workers. We acknowledge that people using the tool might have both psychosocial and physical disability."

For more information, please visit: <https://www.imha.vic.gov.au/ndis-mental-health-toolkit>

NDIS mental health toolkit

This toolkit is designed to provide you with the information, skills and support to advocate for what you want under the National Disability Insurance Scheme (NDIS).

What does the NDIS mental health toolkit do?	▼
How to use NDIS mental health toolkit	▼
If you come across a term you don't understand	▼
Speaking up for yourself	▼

In this section	
NDIS mental health toolkit	
What is the NDIS?	▼
My identity and keeping myself safe	▼
Who will support me?	▼
Applying for the NDIS	▼
Setting my goals	▼

Meaningful Ageing Australia - See me. Know me. Resources

[Meaningful Ageing Australia](#) is an Australian leader in education and resourcing of evidence-based spiritual care for the ageing population in the context of health, aged care and community services.

Their *See me. Know me.* campaign is designed to help seniors feel more valued, to help them connect with family and friends, and ultimately to empower them to find aged care services that will truly tune in to them as a whole

person.



[<https://meaningfulageing.org.au/about/>]

As part of their campaign, Meaningful Ageing Australia have developed multiple resources including conversations starters and cards, thought-starters about 'purpose' and ten questions you can ask aged care providers.

To know more about the See me. Know me. campaign, please visit: <https://meaningfulageing.org.au/see-me-know-me/>

Preferences and User Experiences of Wearable Devices in Epilepsy

Most recent data shows that over [150,000 Australians experience epilepsy](#), and wearable health monitoring technologies are changing the way people can manage seizure activity and alert others when they may need assistance.



[Source: <https://www.epilepsy.org.au/shop/epilepsy-products/seizalarm-app/>]

Australian researchers from Monash University, Alfred Health and other networks have recently published a [systematic review](#) on "Preferences and User Experiences of Wearable Devices in Epilepsy" which has been nicely summarised by Steven Karceski [in this article](#).

The review revealed that about 80% of participants were accepting of wearable technology. Sixty-nine percent preferred a wristwatch-like device that could be connected to a smartphone. Some findings of the review include:

- Participants wanted high accuracy.
- Overall, the group was willing to pay up to 300 USD for the device and \$20 per month for the subscription fees.
- About 50% were willing to wear a patch-type sensor, and some preferred a mattress sensor. Most of the participants did not want an implanted device.
- Many people wanted the device to send an alert in real time (and in 15 minutes or less). Overall, many (85% of patients and 95% of caregivers) felt that having a device like this would improve autonomy.

For more information, please refer to the [summary article](#) and [original review](#).

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.

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spahc.rail@monash.edu

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