

Rehabilitation, Ageing and Independent Living (RAIL) Research Centre

Friends of RAIL eBulletin – December 2024

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.

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



Dr Aislinn Lalor

Dear Friends of RAIL,

As we wrap up another year, we want to extend our heartfelt thanks for you all being a part of the Friends of RAIL community. Your engagement and participation in our activities and contributions to projects and ebulletins have been invaluable. In this December edition of our eBulletin, we have a variety of updates and stories to share with you.

Inside, you'll find a message from Grainne, our Head Friend (Consumer and Community Representative), reflecting on the past year and looking forward to 2025. We also introduce you to Dr. Christina Ekegren, our new Rehabilitation Stream Lead. While we don't have a spotlight on a Friend of RAIL in this bulletin, we do invite anyone who would be willing to share their story (or anecdote) for others to read about in 2025.

Don't miss the details about our upcoming Friends of RAIL event in February, where we'll officially launch the White Paper many of you have contributed to, as well as an opportunity to hear about RAIL projects where Friends of RAIL have been involved. Additionally, we have insightful articles on improving housing outcomes for people with disabilities, reflections on travelling with technology, and tips for carers.

As we celebrate the festive season, we wish you all a joyful and safe Christmas and a Happy New Year. We look forward to catching up with you in 2025 and continuing our journey together in rehabilitation, ageing, and independent living.

Warm regards and Happy reading!
Aislinn

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

Grainne Cruickshank

Time goes by so fast - here we are getting ready for Christmas. While unfortunately we were unable to catch up as planned on the 2nd of December, I do look forward to catching up with many of you at the Friends Start of Year event on the 10th of February.

As a sneak peek of what is to come at the event in February, Christina and Raelene will speak about the Tools for Ageing Well with a Traumatic Brain Injury. While you will hear more about it in February, I just wanted to tell you about how much I enjoyed being involved in the creation of the resource.



I was lucky enough and thrilled to be asked to be on the steering committee of the project and then also to be one of the lived experience consumer representatives. The process for me started about 18 months ago and then with the lived experience team shortly after. I thoroughly enjoyed working on it, when you see your suggestions or experience in print it means so much and then to see the end product and know that it will be so much help to

so, so many – it is really quite something. If you'd like to know more about the Tools for Ageing Well with a Traumatic Brain Injury – please attend the Friends event in February, or also please feel free to look at them via: <https://www.connectivity.org.au/living-with-tbi/tools-for-ageing-well/>.

My husband Peter used to call Stephanie Alexander's cookbook his bible for cooking, this resource to me feels like a bible of reference for people ageing with a traumatic brain injury. Brain injury is so different for everyone and this reference has so much advice - not only for those ageing with their injury.

The team that worked on this are amazing, we were consulted for so much, in the working group we worked with a team of clinicians and I was thrilled, lucky enough, and amazed to be working on it with Peter's Professor of Rehabilitation from Epworth Hospital, Professor John Oliver. The team had Zoom meetings so members from NSW and Victoria could easily be involved (after we dealt with all the technical issues!).

I invited myself to the conference in Adelaide for the launch (I had never been to a conference)! It was so well received. All I can say again is thank you to Christina and all the group that worked so hard to make this happen. It will help so many people dealing with a traumatic brain injury.

Again, I do hope you all have a lovely break over Christmas and I look forward to seeing you in 2025! Happy New Year – Grainne.

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 four times per year), 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 Christina Ekegren

Hello to our Friends of RAIL! My name is Dr Christina Ekegren and I am a Senior Research Fellow with RAIL, and will take on the role of RAIL Rehabilitation Stream Lead in 2025.

I am a physiotherapist by background and have worked in universities and clinical settings in Canada, the UK and Australia. I joined RAIL in 2020, shortly after the centre opened and since then, have seen the RAIL family (and the Friends of RAIL) go from strength to strength!

I have a passion for physical activity research, particularly for older adults, people in hospital and people recovering from injury. One of my current projects is looking at developing a new 'vital sign' for physical activity to address the issue of deconditioning in hospitalised older adults. We have spoken to patients, families and clinicians in eight hospitals around the world to understand 'what matters' and 'what is feasible' with respect to measuring physical activity in this setting.

Outside of work I enjoy dancing. I perform twice a year with my dance troupe and have danced at the Forum Melbourne and Federation Square. I have also just completed a Certificate IV in dance teacher training and look forward to teaching some seniors classes in the near future!

Spotlight on a Friend of RAIL

Would anyone like to share some of their life with all of us? Over the years of being involved in organisations that was one part of the newsletters I read every time. I suppose I felt part of a community and not alone in living a life that had challenges and was different to most.

If you would like to provide a Spotlight of yourself to be featured in upcoming Friends of RAIL ebuletins or simply share a reflection on a topic, or a poem you might have written, or something similar related to rehabilitation, ageing or independent living, please contact Karine via email spahc.rail@monash.edu or phone (03) 9904 4557.

Grainne Cruickshank, Friends of RAIL Consumer and Community Representative



Upcoming Friends of RAIL event - Register now!



You're invited!!!

As most of you are aware, our Friends of RAIL event originally scheduled on 2nd December had to be postponed to **Monday 10th February 2025** from 1.00pm - 3.00pm, AEDT.

Where: The event will be held on the Monash University Peninsula Campus in

Frankston with a Zoom-in option available for those who cannot attend in person (but would like to attend online).

What: It will include some brief presentations from the RAIL team, a workshopping activity as well as opportunities for networking during afternoon tea.

You will also be provided with a copy of the White Paper developed from the Friends of RAIL launch event 2023 (challenges and opportunities across rehabilitation, ageing and independent living). For those unable to attend the Launch in February but would like to receive a copy of the White Paper post the event, please contact Karine via email spahc.rail@monash.edu or phone (03) 9904 4557.



If you would like to attend the event (either in person or online) on the 10th February 2025, please complete the registration form below and we will send you a Google calendar invitation. If you have a friend that you think would like to attend the event with you, please feel free to share the link to the registration form with them. We look forward to celebrating the launch of the White Paper with you all and updating you with how Friends of RAIL have been involved in various RAIL projects across 2024.

[Select here to register for the upcoming Friends event](#)

Reflection from a Friend on travelling and technology



As part of my 80th birthday celebrations my family arranged for me to accompany my daughter-in-law's mother on a trip to France and Spain. This was a wonderful experience that I never thought I would ever have again, but what was so amazing was how technology made travelling so much easier.

Apart from packing my passport I found wonder of all wonders the benefits of my mobile telephone. I could:

- store my boarding pass on my Apple wallet;
- use Notes to scan documents, just in case I lost them;
- download apps for trains and airlines;
- book train tickets and airline tickets when in Europe;
- use Google Maps to help me negotiate my way through unknown cities;

- use the Conversation button or write a message on Google Translate when I couldn't understand someone;
- manage my banking requirements when I had my wallet stolen;
- use the calculator to check that I wasn't being overcharged;
- turn on the flashlight when I found myself in the dark;
- use my phone as a camera, and
- email photos back to Australia to share with family and friends.

The mobile telephone has made communicating so much easier than it has ever been. At no stage did I feel cut off from my family, I could pick up the phone and talk or Facetime them if I needed to.

The clock on the phone adjusted to whatever time zone we were in I didn't need to wake them in the middle of the night! We only needed to get the WiFi number and passcode to use the internet to check on what special tourist attractions each town had to offer. I found I was able to use an App to photograph a flower or bird and learn its name. No spending hours looking at Neville Cayley's "What Bird is That?".

I was able to use my Kindle to purchase and read books without having to carry them in my suitcase.

I used my mobile phone to pay for items for sale at markets or in small villages. Technology has made life so much easier, but it has taken some time to learn how to get the best out of this equipment.

My advice is to buy the best equipment you can afford, spend time learning how to use it, and enjoy the liberating feeling of being in control.

Over the past few years, I have learned from my friends, and especially my grandson who is more patient with his Nanna than my sons.

Technology today gives everyone the opportunity to widen their horizons, you only have to take a bit of time to experiment or ask questions to find your way into a new world.

Margaret Thomas

RAIL Team members on ABC radio

Dr Aislinn Lalor, RAIL Research Centre Senior Research Fellow, along with carer Ivan Freer, and Alice Urban, Director of Integrated Care, Peninsula Health were invited to join the ABC Radio PM Program (and ABC Radio National) as part of Carers Week 2024 to provide an overview of the [Carer Health and Wellbeing Service](#).



[Select here to listen to the interview on the Carer Health and Wellbeing Service](#)

Professor Keith Hill, RAIL Research Centre Ageing Stream Lead was invited to join a panel on the ABC Radio Life Matters program discussing a new study led by the University of Queensland linking frailty and dementia and was asked to provide some discussion about physical activity in to older age, including for people living with dementia.

Select here to listen to the program and hear Professor Hill talk about physical activity in older age

Improving housing outcomes for people with disability: policy and practice initiatives

Independent Living Stream Lead Associate Professor Libby Callaway is part of a national team led by Professor Monica Cuskelly from the University of Tasmania, delivering a project funded by the Australian Housing and Urban Research Institute (AHURI) called "Improving housing outcomes for people with disability: policy and practice initiatives".

The study aims to identify changes to policy and practice that will improve housing outcomes for people with disability, including by providing insights into what the sector and people with a disability consider to be 'good' housing outcomes.

The team has undertaken a rapid literature review. They then hosted one of the two investigative panels in this project, attended by subject matter experts including people with lived experience of disability, providers of housing and support, researchers and policymakers. The next step in the project is a series of interviews, focus groups, and a survey, with people with disability and their key supporters, which will inform the final investigative panel and project report due in April 2025.

To read more about this project, go to <https://www.ahuri.edu.au/research-in-progress/Improving-housing-outcomes-for-people-with-disability-policy-and-practice-initiatives>



Top Tip from the RAIL team

Top Tips



Are you a family member or friend who helps support or provide care for someone? Are you a carer, or do you know someone who cares for others?

It may be useful to explore the website called the Carer Gateway

- <https://www.carergateway.gov.au/> Carer Gateway is an Australian Government program providing free services and support for carers. Sometimes family members (spouse, siblings) or friends (or neighbours) may not see themselves as a carer – but are in fact providing a carer role. There is a section of the website called 'information finder' that can be accessed via <https://www.carergateway.gov.au/information-finder> which might be helpful for you or someone you know who is supporting someone.

Alternatively, you can call 1800 422 737 from Monday to Friday from 8am-5pm to check on eligibility to access services offered by the Carer Gateway team of service providers located across Australia.

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

Resources for supporting end of life care for people with dementia

Dr Nathan Davies and his team from the University College London have developed a suite of user-friendly tools on palliative dementia care to support healthcare professionals and informal carers.

One of the tools *Caring for someone with dementia through to the end of life* is a decision aid for healthcare professionals with family members or friends caring for someone with dementia in the later stages, or towards the end of their life. Additional resources specific for carers, family members, and friends also include:

- A 52-page guide to help make decisions about “Eating and Drinking” for people with dementia towards the end of life:
<https://www.mariecurie.org.uk/globalassets/media/documents/how-we-can-help/booklets-pdfs-only/eating-and-drinking-in-dementia.pdf>
- A 19-page guide for carers/family members to support decisions while caring for someone with dementia during Coronavirus (COVID19) and beyond:
https://www.ucl.ac.uk/psychiatry/sites/psychiatry/files/endemic_decision_aid_26_08_20_v.2.pdf

You can read more about the *Caring for someone with dementia through to the end of life* decision aid and other resources through the Australian Ageing Agenda:

<https://www.australianageingagenda.com.au/clinical/tools-address-palliative-dementia-care-challenges/>

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.

We acknowledge and pay respects to the Elders and Traditional Owners of the land on which our four Australian campuses stand. Information for [Indigenous Australians](#)

We're committed to [diversity and inclusion](#)

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

Our mailing address is:

spahc.rail@monash.edu

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