

Australia and New Zealand Chapter IFNA May 2022



Newsletter Number 18: May 2022

Australian and New Zealand Chapter News

Welcome to the May newsletter with a focus on vulnerable people in healthcare and in our communities

This month we wanted to share some personal journeys as well as sharing how vulnerable people have inspired their families and communities to seek for help.

The journey of a transplant recipient and support of family

Hello, My name is Jordan Bate and I studied a Bachelor of Nursing and am a part of the graduating class of 2020, Griffith University.

What got me into nursing? Many people have their own experiences and reasons however, for me it was quite personal due to my own experience within the healthcare system but as a patient.

I was originally born premature (with my twin brother Harrison) I was showing signs of failure to thrive and through the first couple of months, I was then showing indications of a rare liver disease called Alagilles Syndrome. At the age of 2 (2001) through genetic testing and studies my diagnosis was confirmed.

Alagilles Syndrome (in a nutshell) is a multi-organ condition that can affect all organs within the human body; for myself predominantly I had liver issues and mild pulmonary stenosis. Like patients with down syndrome, Alagilles Syndrome patients have similar facial features, of which I look the part. However, my brother was fortunate enough to not carry this gene or show any signs of Alagilles Syndrome.

Throughout my life between regular visits, multiple surgeries, and many hospital admissions there was always talk about Organ and Tissue donation, and one day that I will eventually need a lifesaving Liver Transplant. Skip to 16 years later (at the age of 14) during year 10 – I had re-visited this option with the Hepatology team at the Royal Brisbane Children's Hospital (at the time), and solely focused on the quality of life that I was living, Until that very day majority of my medical treatments and decisions were discussed between myself and my mum but mostly made by my mother Leisa. The day I listed for transplant was the day where the most un-easing and nerve-racking wait began to receive that lifechanging call for a Liver Transplant - eventually 22months later (which we thought was never going to come) we received a phone call around 0200am that a liver had become available, and it was time to make our way to hospital.

Hours which felt like days had past and after a full day of pre-operational workup for this transplant we got the go ahead and I was heading into surgery with my mum by my side, going into this together like we have since day one.

Post-transplant the liver remained a success, leaving the hospital about 1.5weeks since the operation everything was heading into the right direction until a week later where I suffered from a rare complication to do with my bowels (as I have had numerous surgeries abdominally, my inside was no longer text-book perfect). Having to have a bowel resection and removal of 1meter of my small bowel lead me into a 3month hospital stint which saw me almost losing my life and being in a critical condition on mother's day 2016, one could never imagine what my family and most importantly my major support person was feeling, let alone making all the decisions she need to, to keep me alive while I was in and out of theatre.

Throughout this 3-month hospital stint and at one stage getting down to 36.7kg (from 56kg) it saw myself at the lowest point in my life I have ever felt. Over the next couple weeks and during the recovery process both physically and mentally was the biggest push and I would not have been able to do this without my supportive mother and family.

Both patient-centred care was provided by the nurses and doctors at the Princess Alexandra Hospital (Ward 4BT – Transplant Ward) and the allowance of my mother to stay with me day and night and allowing my family to be so involved with my recovery – This experience was my light switch moment happened, where I had the realisation that I want to be just like these amazing nurses. Once my health was further on track my next goal was becoming a Registered Nurse.

I seriously wouldn't be here today, and I am forever grateful, no words can express how amazing my care was and no words will ever be enough to say thank you to my donor and the donor family. Without the care of my family and having such a supportive network around me I would imagine my outcome would have been very different.

Thank you for letting me share a little snippet of my experience and importance of family within the hospital/healthcare system.



Neuro-injury treatment

How Coralie's son inspired her to take charge in PSE research for neuro-injury treatment

https://thenursebreak.org/perispinal-etanercept-treatment/?utm_source=rss&utm_medium=rss&utm_campaign=perispinal-etanercept-treatment&mc_cid=02569bed35&mc_eid=e368e7990f



Meet Dr Coralie Graham, a RN turned Associate Professor and Visiting Scholar at Griffith University School of Pharmacy and Medical Sciences¹, currently researching Perispinal Etanercept Treatment (PSE) for Stroke. Coralie's son Joel suffered a devastating brain injury at 3 years of age which lead Coralie to return to studies to get her PhD to help her son.

After discovering PSE as an off-label treatment in the USA for brain injury and stroke, Coralie became involved in the clinical trial research in Australia.

¹<https://www.griffith.edu.au/griffith-health/school-pharmacy-medical-sciences/research/stroke>

Refugee Health

by Hazel Rands

I am a Senior Lecturer and International Program Advisor and have worked in the international space at Griffith University for over 20 years. I have led our international placements to Laos, with a strong focus on family assessment in Thailand and Vietnam since 2009. I was Program Director for our off-shore Nursing Program in Singapore for 3 years and also work very closely with our international students. This background supported a natural transition to a research project with refugee health nurses to explore their experiences with newly arrived families, often during their first interaction with the Australian health care system. I have been working on this project with Dr Elisabeth Coyne.

Refugee health services are underpinned by Primary Health Care principles - a model of service delivery which is used across numerous settings to meet the diverse needs of newly arrived families (Joshi et al., 2013; Kay, et al., 2010). Our study identified that there is limited literature about community nurses' experiences, their roles and the extent to which they use a framework such as a Family Nursing assessment tool for gathering information and tailoring care for refugee families. We are currently finalising an Integrative Review which identifies this gap. Interviews were conducted with 11 Registered Nurses working in two refugee health services in SE Queensland and completed a thematic analysis (results article in progress). Our study identified that providing care for clients using a holistic framework helps provides a focused approach, which can systematically improve quality and safety in caring for families. It was clear throughout the interviews that a more focused, systematic approach increases the ability of nurses to find solutions and understand family strengths (Bell, 2013; Robertshaw et al., 2017). Whilst this study initially intended to explore the use of Family Assessment frameworks, an incidental finding within the cohort was that a family focused framework can increase the nurses' sense of benefit with the client interaction, which can in turn, reduce the nurses' personal distress (Jovanovic et al., 2004; Wright, 2015)



Navigating Ever-Changing Seas – Ageing with Intellectual Disability in the Context of Family

Navigating Ever-Changing Seas – Ageing with Intellectual Disability in the Context of Family

People with intellectual disability (PWID) have a shorter life expectancy (20 years), experience age related decline earlier than the general population (from approximately 40-years), are now living longer, and the majority reside with someone they identify as family.

Using Photo Elicitation as part of a Constructivist Ground Theory approach, this study explored perspectives of 19 individuals and 28 family members about ageing and each of whom shared their realities and future aspirations for themselves and their family members.

Navigating ever-Changing Seas is the resulting theoretical model that demonstrates the nature of caregiving, receiving and decision-making for PWID and significant others. Whilst not predictive of future planning, it is indicative of the history that underpins and informs current and future decision-making for PWID and their 'family'.

The broken line signifies fluidity between all parties in the caregiving relationship, the intrinsic and extrinsic factors that influence their individual and collective lives - which includes nurses and other health professionals.

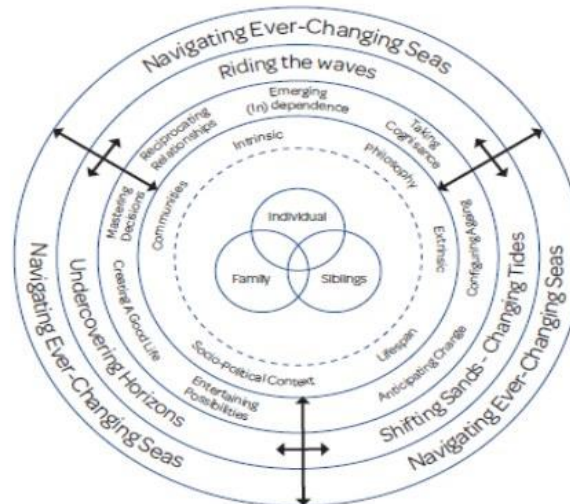
Navigating Ever Changing Seas is informed by three core theoretical concepts:

1. *Riding the Waves* represents the ebb and flow of relationships enabling people to get on with daily life by taking things as they come through; Reciprocating relationships, Emerging (in)dependence and Taking cognisance.
2. *Shifting Sands – Changing Tides* reflects un-discovered realities of the past, present and those still evolving informed by; Configuring ageing and Anticipating Change.
3. *Uncovering Horizons* denotes the sense of transition from the present to an inevitable future that holds potential for each party by; Entertaining possibilities, Creating a good life and Mastering decisions.

Understanding the interrelated roles, relationships, experiences and expectations of and between the individual and those of significance to them - directly informs the therapeutic engagement by nurses across health and disability systems across the lifespan. This model also has relevance for working alongside people with long-term conditions.

Trip, H., Whitehead, L., & Crowe, M. (2020). Perceptions of ageing and future aspirations by people with intellectual disability: A grounded theory study using photo-elicitation. *Ageing & Society*, 40, 966-983. <https://doi.org/10.1017/S0144686X18001460>

Trip, H., Whitehead, L., Crowe, M., Mirfin-Veitch, B., & Daffue, C. (2019). Aging with intellectual disabilities in families: Navigating ever-changing seas – A theoretical model. *Qualitative Health Research*, 29(11), 1595-1610. doi: 10.1177/1049732319845344



Australian and New Zealand Chapter research project

This survey has now been running for over three months and we have had 103 participants. We are asking you again if you could please send to any groups, colleagues or social media contacts to ask for participation in this research by completing our survey.

What is nurse's role with family?

Here is an opportunity to be involved in a research study to help us understand what nurses see as their role with families.

“Nurses attitudes toward the importance of families and perceived outcomes of family involvement in nursing care” [FAMinCare]. ([GU: 2021/371]

As nurses, you are involved in caring for patients who are mainly supported by family members. When nurses can create a relationship and work with the family towards both physical and psychosocial healing, there is a subsequent decrease in suffering among family members. Evidence suggests family involvement in care is beneficial for the patient however implementing this is often difficult. This study seeks to understand nurses' attitude towards family involvement in care and the development of a family-nurse relationship.

Participation in the study will involve the completion of an online survey less than 20 minutes.

If you would like to participate in this study, we ask that you read the information sheet at the start of the online survey and complete the online survey.

<https://prodsurvey.rcs.griffith.edu.au/prodls200/index.php/415994?lang=en>

Join our family nursing chapter and increase your connection with family nursing colleagues.

Link to family nursing²

REASONS why YOU should Become a Member of IFNA

Currently fees for Chapter members NEW IFNA Member - \$75.00 (USD) is 40% off the usual membership fee for a limited time.

<https://protect-au.mimecast.com/s/iUQDC81ZPoh67nkRqInSSZq?domain=internationalfamilynursing.org/> (*about:blank*)

Benefits of joining IFNA

To interact with a global community of nurse scholars and practitioners who care about the health and healing of families.

Develop international friends and mentors.

To attend webinars about family nursing theory, practice, and research

Don't forget to connect with the main International Family Nursing Association and join to access extensive family nursing resources. <https://internationalfamilynursing.org/> (*about:blank*)

And have a look at the refreshed IFNA website.

Especially the new Australian and New Zealand Chapter page with new features.

Recent articles

Family-centred care change during COVID-19

<https://doi.org/10.1111/nicc.12766>

What is known about the topic

²<https://youtu.be/bLHOvxQGlic>

- In NICUs around the world, FCC is incorporated into clinical practice and widely used.
- Implementation of FCC in low-resource health care settings is challenging due to complex and diverse political, social, cultural and economic characteristics.
- COVID-19 has impacted care delivery for neonates and their families in NICUs, including visitation policies, developmental care and communication practices.

What this paper adds

- Implementation of practice innovations in NICU has improved parents and health care providers perceptions of the FCC elements of respect, collaboration and support.
- Despite COVID-19, parents responded positively to the FCC innovations implemented into daily practice.
- Communication is necessary to work collaboratively with parents to promote partnerships in care during the social distancing and public safety of COVID-19.

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Next meeting Wednesday • July 8 , 2022 1100-1200 AEST Teams link ³

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³[https://teams.microsoft.com/l/meetup-join/19%3ameeting_NzZjYmQzOTEtMzgyOS00NDQ2LWlzMGEtZDZkNWUyZTRjZjM5%40thread.v2/0?context={\"Tid\":\"%3a\"5a7cc8ab-a4dc-4f9b-bf60-66714049ad62\"%2c\"Oid\"%3a\"2fa526d7-e268-410f-9277-42360c0b3876\"}](https://teams.microsoft.com/l/meetup-join/19%3ameeting_NzZjYmQzOTEtMzgyOS00NDQ2LWlzMGEtZDZkNWUyZTRjZjM5%40thread.v2/0?context={\)