

# PALLIATIVE CARE IN PRISONS PROJECT

UTS: IMPACCT



## Message from Project Lead

PROFESSOR JANE PHILLIPS

Welcome to the fifth issue of the Palliative Care in Prisons (PiP) Project Newsletter.

In this issue, Professor Megan Williams provides an overview of the inaugural meeting of the National Aboriginal and Torres Strait Islander Leadership Group ('Leadership Group') convened in August 2021. This is an important milestone, as the national Leadership Group will guide the PiP Project to ensure that the perspectives and knowledges of Aboriginal and Torres Strait Islander peoples are represented and embedded in our data collection and analysis. Their voices will be critical to the co-design, development, and communication of the National Framework for Provision of Palliative Care in Australian Prisons.

This Newsletter introduces another of our Project and Site Investigators, Dr Michael Chapman, from the Australian Capital Territory (ACT), and Mr Stephen Peterson, our consumer representative from Victoria. As COVID-19 continues to impact every aspect of our lives, Stephen provides insight into the pandemic's affect upon his role as an Independent Prison Visitor in two Victorian prisons.

Behind the scenes, the Project team has continued to progress the various applications for ethical approval, which has proven a complex and time-consuming process. However, in partnership with Corrective Services NSW, we hope to obtain the final NSW ethical approval in the coming weeks. Once this has been secured, the Gap Analysis can commence in NSW and we will progress the remaining ethical applications in the other jurisdictions. During this time, Project Officer Isabelle Schaefer has completed a systematic review and meta-synthesis to explore the perceptions and experiences of people in prison receiving palliative care in custody. A summary of the themes identified in the systematic review which forms part of Isabelle's doctoral thesis, are outlined further on page 4 of the Newsletter.

Additionally, I am pleased to announce that we have published an [editorial](#) in the *International Journal for Palliative Nursing* to advocate for the development of palliative care provision in prisons globally. On a final note, we invite you to visit the newly launched Palliative Care in Prison Project website, located at [www.uts.edu.au/palliativecareinprisons](http://www.uts.edu.au/palliativecareinprisons).

With the COVID-19 pandemic forcing many of our colleagues from the East Coast into extended lockdowns, we hope this Newsletter finds you safe, strong and well, wherever you are located.

Kind regards,

Jane Phillips



# THE NATIONAL ABORIGINAL AND TORRES STRAIT ISLANDER LEADERSHIP GROUP

## PROFESSOR MEGAN WILLIAMS

"Yiradhu marang"

*Greetings all, in the language of the Wiradjuri people*

It is deadly excellent to announce that the inaugural meeting of the National Aboriginal and Torres Strait Islander Leadership Group ('Leadership Group') took place on 17 August 2021. This Leadership Group has been formed to advocate that Aboriginal and Torres Strait Islander people's perspectives and knowledges are in all aspects of the Palliative Care in Prisons (PiP) Project, including data analysis, interpreting findings and sharing results, especially to Aboriginal and Torres Strait Islander peak bodies and communities. The Leadership Group will have a key role in co-designing the National Framework for Provision of Palliative Care in Australian Prisons, which must include cultural safety and Aboriginal and Torres Strait Islander people's models of end of life care.

The Leadership Group includes Aboriginal and Torres Strait Islander people from across Australia – at least two of us already from most states and territories – though we do seek more members especially from NT and Tasmania. We have professional and or personal experiences with palliative care, prison health care and/or ethical research with Aboriginal and Torres Strait Islander people. We are a mix of ages, mobs and locations to try to help understand the diverse palliative care experiences and needs of Aboriginal and Torres Strait Islander people in prison.

At our first meeting, we discussed the extreme sensitivity of issues about palliative care in prisons, which include cultural, human rights, legal, and family business. We nominated Co-chairs – Jack Bulman from Mibbinbah Spirit Healing, and also myself (Megan Williams) as an interim given my involvement with the PiP Project to date. We expect to meet quarterly, with Terms of Reference, but all agreed there are so many issues to discuss and experiences to convey that we hope to meet more frequently. We envisage deep, safe discussion on issues that rarely get aired, and we feel the need to share our insights for the benefit of others, where appropriate. The PiP Project will support us to express our needs and expertise through the creation of a podcast and the publication of articles and papers.

The Leadership Group is supported by the broader PiP Project Aboriginal and Torres Strait Islander Community Engagement Strategy Working Group. This working group is made up of PiP Project collaborators from all cultures who have connections with Aboriginal and Torres Strait Islander people and communities and who have a real motivation for ensuring Aboriginal and Torres Strait Islander people's ways of knowing, being and doing are used throughout the PiP Project.

If anyone is interested in joining these groups, feel free to contact me at [megan.williams@uts.edu.au](mailto:megan.williams@uts.edu.au).



# INDEPENDENT PRISON VISITOR SCHEME, VICTORIA

## STEPHEN PETERSON



Since ceasing paid employment in March 2014 I have taken on numerous community-related activities. An advertisement in The Age led to me becoming an Independent Prison Visitor (IPV), commencing in October 2014. Initially I visited Port Phillip Prison monthly, but now I also visit Ravenhall Correctional Centre on alternate months. Under the auspices of Corrections Victoria (CV), the IPV Scheme has been operating in Victoria for about 30 years, acting as the eyes and ears of the community to view and report on conditions in Victorian prisons, as well as the important role of speaking with prisoners and staff.

Independent Prison Visitors notify the prison of the time and date of their planned visit, and this information is conveyed to prisoners via internal communications systems. Usually, a few prisoners will make an appointment to meet with the IPV, in their unit. This gives prisoners the opportunity to talk about any issue of concern to them, be it of a personal nature or a generic issue associated with prison life, which the IPV then reports to the prison management and Corrections Victoria. This reporting process is always explained to the prisoner, so nothing they want to remain confidential goes beyond this conversation. Whilst an IPV cannot do anything beyond speaking with management and submitting our report after each visit, I know as a certainty that this intervention on behalf of prisoners can and does contribute to solving their problems and improving their lives.

The prison system in Victoria has done a wonderful job in mostly keeping prisons COVID-free, of necessity by employing strict control measures. The resultant restriction on movement has been hard on prisoners, but the ability to earn reductions in sentences in return has helped lessen the blow. Of course, the use of video-conferencing for visits has been a real bonus for prisoners, and there is no doubt this service will remain. We IPV's also have been undertaking virtual visits with any prisoners who make appointments, but this does not make up for the lack of contact, and resultant conversations, that can arise from just wandering around the prison.

From speaking with prisoners, I have heard about lives and lifestyles entirely different from anything I have experienced myself. One conclusion I have arrived at is how important growing up in a loving, supportive family is for young people's development.

Deprivation of liberty is punishment in itself, and sooner or later virtually all prisoners will be released, so the emphasis in prison must be to help equip prisoners with the life skills they need to make a success of their life upon release. I believe that, given the opportunity in prison to acquire employable skills, and with some ongoing assistance on the outside, especially with stable accommodation, most prisoners have a chance of becoming functional members of society.

This must continue to be the ultimate goal of the prison system.

## DR MICHAEL CHAPMAN

MBBS FRACP FChPM PhD

Michael is a geriatrician and palliative medicine physician who works as director of palliative care at Canberra Hospital. His published academic interests include using systems thinking in healthcare, the integration of specialist palliative services into aged care, the ethics of dementia care, and quality dying in the acute setting. Michael has academic roles with The Australian National University and University of Technology Sydney and sits on the palliative medicine training committee for the Royal Australasian College of Physicians.

Michael is passionate about this project as he believes that providing the best palliative care means making sure that the most vulnerable members of our community don't miss out on the care that they need. We need to make sure that the needs of people in prison aren't forgotten, and this project is a key part of achieving that equity.



## NATIONAL PALLIATIVE CARE AWARDS 2021

We wish to acknowledge the outstanding achievements of two PiP Project contributors at the recent National Palliative Care Awards.

**Congratulations and well done to:**

**Ms Cheryl Porter-Pedras** (member of Aboriginal and Torres Strait Islander Community Engagement Strategy Working Group and National Aboriginal and Torres Strait Islander Leadership Group) won an individual award for *Excellence in Aboriginal or Torres Strait Islander Palliative Care*.



**Dr Paula Moffat** (Western Australian Site Investigator) won an individual award for *Excellence in Palliative Care – Community Based Care*.



## META-SYNTHESIS: PERCEPTIONS OF PALLIATIVE CARE IN CUSTODY

Even though palliative care is a human right, people in prison experience additional barriers to person-centred palliative care. Project Officer Isabelle Schaefer has explored the perceptions and experiences of people in prison regarding palliative care provision in custody by conducting a systematic review and meta-synthesis of existing literature.

The meta-synthesis revealed two main themes: expectations versus experiences of palliative care, and the effect of the prison environment on access to and provision of palliative care in custody. People in prison expected to receive equal palliative care to people in the community, but that this wasn't reflected in their experiences. The prison context also presented significant barriers to palliative care access and provision, particularly the physical environment and psychological burden of dying in prison.

This work provides an important window into how people in prison feeling about palliative care and dying in prison which can inform the approach of the National Framework for Provision of Palliative Care. A manuscript detailing these findings is currently being reviewed by *Palliative Medicine*.

# PRESENTATIONS AND PUBLICATIONS

- National Palliative Care Projects Grant Recipient Forum – 11-12 March 2021, "Palliative Care in Prisons Project – Progress and Activities".
- Correctional Services Healthcare Summit – 25/26 May 2021, "National Palliative Care in Prisons Project".
- Justice Health and Forensic Mental Health Network Palliative Care Education Forum – 1 June 2021, "National Palliative Care in Prisons Project – Developing and implementing National Research".
- National Palliative Care Projects' Yarning Circle – 16 June 2021, "Palliative Care in Prisons Project – Aboriginal Leadership Group Development Strategies".
- Phillips JL, Schaefer I. Dying an expected death in prison: a growing reality. *International Journal of Palliative Nursing*. 2021 Aug 2;27(6):278-279. doi: 10.12968/ijpn.2021.27.6.278. PMID: 34459243.
- 2021 Oceanic Palliative Care Conference <https://oceanicpallcare.com/> 7-10 September 2021- Oral Presentation- "Determinants of palliative care provision in prison: a systematic review".



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In partnership with:

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## NEXT MEETINGS

Aboriginal and Torres Strait Islander  
Community Engagement Strategy Working  
Group

Wednesday 24 November 2021  
14:00-15:00 (AEDT)



Correctional/ Justice Health Services  
Working Group

Wednesday 10 November 2021  
14:00-15:00 (AEDT)



National Consortia Project Advisory Group

Wednesday 1 December 2021  
14:00-15:30 (AEDT)



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