

# Disability End-of-Life Care Project

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PROJECT REPORT 2016  
NORTH EAST METROPOLITAN AREA (NEMA)

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## IMPROVING END-OF-LIFE OUTCOMES FOR PEOPLE WITH INTELLECTUAL DISABILITIES WHO LIVE IN RESIDENTIAL SERVICES (2016)

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A Partnered Project between North East Primary Care Partnership (NEPCP), DHHS Disability Accommodation Service (DAS) in the North East Metropolitan Area (NEMA), DHHS DAS Policy Development, Centre for Developmental Disability Health (Victoria), Banksia Palliative Care Service Inc. and La Trobe University Palliative Care Unit (LTUPCU).

*The NEPCP funded La Trobe University Palliative Care Unit to coordinate the project from December 2015 – June 2016. A research component helped develop practical resources in partnership with DHHS DAS NEMA. Maree Belleville, DAS Manager (NEMA) was the internal research contact and provided leadership in developing resources.*

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Once again, we would like to extend our sincere gratitude to our appointed internal research contact Maree Belleville (DAS Manager, NEMA). Maree's formal role of facilitating the research, alongside her commitment to the provision of end-of-life care for residents in group homes, has been and will continue to be paramount to the success of this project. Maree has shared the vision of the research and collaborated generously to contribute to project findings.

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This project has succeeded because of the partnerships created, which will continue as we work towards the collective goal of supporting residents with intellectual disability living in group homes to die in their own beds. Each member of the NEPCP Project Reference Group has willingly contributed their expertise to translate research findings into the development of practice resources.

To supplement the hours funded by NEPCP, the La Trobe University Palliative Care Unit provided an equivalent number of hours from Andrea Grindrod, Health Promotion Officer (HPO), Dr Helen Varney (Honorary Associate) and Director Dr Bruce Rumbold, specifically to undertake the research.

***Andrea Grindrod***

Project Co-ordinator

Health Promotion Officer

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## Introduction

This project has its origins in an earlier North East Primary Care Partnership (NEPCP) project coordinated by Alison Elliott, who explored access to primary care for people with intellectual disability living in north-east metropolitan Melbourne. Among many issues identified, the ageing of this group, and problems involved with accessing aged care services and end-of-life care, were noted. When the NEPCP executive officer, Julie Watson, became aware of partnered work on end-of-life care in disability residential services being conducted between Disability Accommodation Services (DAS) NEMA and the La Trobe University Palliative Care Unit (LTUPCU), she saw the possible synchronicity and commissioned the Unit to make connections in two ways: setting up a reference group representing the various partners involved in improving access to end-of-life care for people with intellectual disability; and developing a story-based resource for training DAS staff in particular and, more widely, other health and welfare practitioners.

The issues documented in the north-east area of course are not limited to these suburbs. Australians ageing with an intellectual disability are likely to encounter the changes and challenges that many older people face. Although this encounter comes, on average, some years earlier than for most people (WHO, 2011), the responses are unlikely to be very different (Cartlidge & Read, 2010). For those of us who learn that we have a life-limiting illness, the question of how we will be cared for is a topic close to our hearts. Our social context – the setting in which we live, our network – will have an increasing influence on our wellbeing as our physical, emotional, and spiritual needs become greater. If asked about the place where we would prefer to die, a large majority of us (70%) answer ‘home’, yet only 14% have this wish fulfilled (Swerissen and Duckett, 2014, p.4).

Although not represented in this study, we should wonder: what would these figures look like for Australians with intellectual disability? Based on what we know, there are a range of challenges that make dying ‘in place’ very difficult for residents, and because of these challenges at policy, planning and practice level, we suppose that the gap between what Australians desire at end-of-life, and what occurs, would be even greater for those living with intellectual disability. The goal therefore, assuming that residents, like most Australians, wish to die at home, is to close this gap.

Aside from the collaborative work being done in NEMA supporting residents to receive end-of-life care at home, we consistently see scenarios where residents are transferred to aged care at the onset of deterioration, excluding home as an option as end-of-life approaches; residents transferred to and from hospital at increasingly regular intervals before they die in hospital; and the unravelling of attempts to keep residents at home when misaligned policies

re-direct care out of the home and into hospital, where there is neither the time nor expertise to meet their everyday communication and care needs. Treatment in mainstream services distances residents from the disability staff who are their advocates and primary support people. It also distances residents from their social networks – the friends they live with, sometimes for decades, who rely on disability support workers to make it possible for them to visit their sick friend in hospital. In this way, treatment and physical care become separated from emotional care and social support.

Through the research (see research report), we wanted to know what it is like when dying happens in a disability residential home – for the dying person, for fellow residents, and for all those who provide care. And for the project, informed by research findings, we wanted to identify what practical information would help to make this the best possible care for all involved.

## Aim

The project has two main goals:

- 1) To establish a reference group representing the various partners involved in improving access to end-of-life care for people with intellectual disability; and
- 2) To develop story-based resources for training DAS staff in particular and, more widely, other health and welfare practitioners.

## Project Outcomes

The range of project outcomes can be attributed to the creation of partnerships. Bringing together the various organisations and their networks has facilitated collective advocacy, and combined expertise to influence end-of-life policy and practice at state, regional and local levels.

### Project Reference Group (Partnership)

The project reference group was established in September 2015, and held five meetings by July 2016, with a 90% attendance rate of all project partners. One working sub-group progressed the development of palliative care policy for DHHS DAS over a series of five meetings. Through partnership, disability training was also provided to Banksia palliative care staff.

Project partners include:

- North East Primary Care Partnership, Julie Watson - Executive Officer
- DHHS DAS North East Metropolitan Region (NEMA), Maree Belleville - DAS Manager
- DHHS DAS NEMA, Melanie Golland - House Supervisor
- DHHS DAS NEMA, Michelle Bevis - Acting House Supervisor
- DHHS DAS NEMA, Andy Moore - Positive Behaviour Support
- DHHS DAS, Residential Services Practice Manual (RSPM) Nathan Lillee - Senior Policy Advisor
- Monash Health, Centre for Developmental Disability Health (CDDH) Victoria, Dr Jane Tracy - Director
- Banksia Palliative Care Service Inc., Julie Paul - Executive Officer
- La Trobe University Palliative Care Unit (LTUPCU), Dr Helen Varney – Honorary Associate
- LTUPCU, Dr Bruce Rumbold – Director
- LTUPCU, Andrea Grindrod – Project Coordinator and Health Promotion Officer

The project reference group brings together the primary sectors that are involved with providing end-of-life care to residents with intellectual disability living in accommodation services, including disability policy and practice experts, specialist palliative care, general practice, and support workers. Partnership assets and combined expertise include direct care provision (disability), clinical palliative care, education, training and research.

## ✓ Outcomes One, Two and Three

1. *The Reference Group was formed and met regularly. The members have agreed to continue to meet in order for emerging issues to be discussed, suitable solutions found and ways to implement these are actioned.*
2. *An article on end-of-life care was included in the DAS Newsletter, distributed to all DAS staff across Victoria.*
3. *Disability training was provided to Banksia palliative care staff by DAS NEMA*

## Policy Development

Drawing upon the expertise and commitment of the Reference Group, state palliative care policies influencing the capacity of residents to die at home were addressed. Key policy and legislation issues identified as practice barriers required research, analysis and consultation

to inform changes necessary for policy adjustments and clarification in both the disability and palliative care sector.

- 1) The Palliative Care Section of the Residential Service Practice Manual (RSPM) was reviewed and rewritten in partnership with the group. The RSPM is a state-wide policy and protocol document that governs practice in all group homes across Victoria. This provided a process to ensure that practice resources developed from the project derive from, and articulate with the improved and updated DAS policy. Changes included a revision of definitions to align with state understanding of palliative care, changes in the Advance Care Planning section and clarification of roles and responsibilities of staff, to name some. For policy developers at DHHS DAS, this was the first time they had a consultancy group with representation from external services to inform policy development on palliative care.
- 2) The researchers at LTUPCU identified an inconsistency in prescribing practice by community palliative care services in group homes. Current DHHS Disability Accommodation Services (DAS) policy supports disability staff being trained by nurses; but policy in some palliative care services prohibits this. Therefore, training policy for the administration of PRN medication was disadvantaging some residents in parts of the state, whilst others were not affected. The rationale for seeking clarification is to ensure that people with intellectual disability are not disadvantaged by different interpretations of Victorian legislation, and to create a policy framework that supports legal, safe and good practice for both community palliative care and disability services. Differences in practice between palliative care services can create confusion in the disability sector, leading to inconsistent care for residents and potentially increased hospital transfers for symptom management. A briefing document was prepared by LTUPCU to be tabled at the DHHS Palliative Care Clinical Network (PCCN) for review, with the request that prescribing guidelines for group homes also be developed. This outcome has been initiated at state level, and continues to be addressed by the group.

## ✓ Outcomes Four and Five

4. *State policy in the disability sector has been reviewed and updated to support ground level end-of-life practice within DHHS managed services.*
5. *Recommendations have been tabled at DHHS Palliative Care Clinical Network advocating consistent prescribing practice by palliative care in residential*



*services (DAS and NGO) across the state, along with a recommendation to develop prescribing guidelines relevant to the disability sector.*

### Regulating end-of-life review by General Practitioners

Drawing on a recommendation from previous research by the LTUPCU, the group looked at the annual health check given to all disability home residents by the GP, the Comprehensive Health Assessment Program. The CHAP questionnaire is essentially a health assessment tool for people with intellectual disability and is a mandated annual review for people in Department of Health and Human Services residences, and is licenced to be used by any person receiving Disability Accommodation Services in Victoria. We advised that a question be added: Would you be surprised if this person was to die in the next 6-12 months? The question has been developed for GPs by the Gold Standards Framework Centre in End-of-life Care in the UK (Prognostic Indicator Guidance 2011). The question is to be asked when a person has 'advanced disease of progressive life-limiting condition'. A useful aspect in the setting of intellectual disability is the advice that 'the answer to this question should be an intuitive one', taking into account social as well as clinical factors. And a 'no' response prompts a further question: 'what measures might be taken to improve the patient's quality of life now and in preparation for possible future decline?' Our suggestion has been passed on to the team at Queensland University which is responsible for the format of the CHAP. The group continues to advocate for inclusion of this question in a newly created end-of-life section in CHAP. This is currently under consideration by the developers, and ongoing conversations between individual members of the reference group are continuing.

## ✓ Outcome Six

*6. The Reference Group recommended the inclusion of an end-of-life section in the mandated annual GP review for residents in DAS, using the Comprehensive Health Assessment Program (CHAP). The CHAP developers have considered the recommendation and are including an end-of-life section in the 2017 version.*

### Contribution to the State Disability Plan

The LTUPCU submitted a paper in the consultation phase of the State Disability Plan on behalf of the group. This paper proposed a state implementation strategy to improve end-of-life

outcomes for people with intellectual disability living in residential services. The submission letter highlighted the Reference Group as an ongoing state-wide committee with expertise to support and advise on end-of-life issues for people with intellectual disability, and recommended that the transition to the National Disability Insurance Scheme (NDIS) be examined in the context of supporting people with intellectual disability to be included in their end-of-life planning, and to be provided with the opportunity to choose, and be offered, care in their preferred site. The hope is that the submission will result in the inclusion of end-of-life in the Victorian State Disability Plan.

## ✓ Outcomes Seven and Eight

- 7. A paper proposing a state implementation strategy for the improvement of end-of-life outcomes for people with intellectual disability has been submitted during the consultation phase to inform the Victorian State Disability Plan.*
- 8. This process has placed end-of-life care on the agenda of NDIS transition*

### Research Project: Narratives from the North East

Research interviews commenced early in the project (n=4) with disability support staff who had provided end-of-life care for the duration of the resident's life in the group home. Research participants were identified by DAS NEMA staff on the reference group. Despite our previous research in DAS NEMA, we would attempt to hear these narratives anew, as individual stories revealing the end-of-life journey of the person at the centre. Our aim was to get a sense of all aspects of this journey, emotional and practical: the effects of the situation on those involved and the specific on-the-ground decisions that had to be made. We asked what it is like when dying happens in a disability residential home – for the dying person, for fellow residents, and for all those who provide care. We wanted to identify what practical information would help to make this the best possible care for all involved.

Using narrative analysis techniques, six themes were identified

1. When does dying become a topic of conversation?
2. When does death become a topic of conversation?
3. Coordinating roles in a context regulated by the Department of Health and Human Services
4. Coping with extra demands

5. When death comes
6. The funeral and after

The research report has been submitted to the Centre for Human Services Research and Ethics (CHSRE) for approval to be published. The Reference Group intends to disseminate the report widely, supporting the uptake and use of the practical resources.

## ✓ Outcomes Nine and Ten

9. *A research report, **Narratives from the North East: Using stories as resources for end-of-life care in disability residential homes**, has been produced.*
10. *The narrative-based practice resources and research are being presented at the **International Association for Scientific Study for Intellectual and Developmental Disability (IASSIDD) in August 2016, Melbourne**. Three of the reference group members are jointly presenting.*

## Development of Practice Resources

Practice resources based on the narrative research have been developed, in partnership with, and driven by the needs of the disability sector. Partners in DAS NEMA in particular are leading the work on practice resources, ensuring they are relevant and applicable in the group home context. The finished products will be made available through the DHHS DAS intranet for staff. These are:

- a protocol for the planning meeting with the palliative care service and the residential home, with the disability service as chair;
- a palliative care training checklist; and
- a checklist for what to do when there is an expected and planned death in the home.
- Introduction to the Palliative Approach –a format for a session with disability house staff where a trained staff person or a member of the DAS Palliative Care Community of Practice steps through preparations for an expected death.
- The Disability Distress Assessment Tool (DisDAT) and palliative care person centred planning document ‘When I Die’ have also been added to the DHHS Residential Services Practice Manual intranet page as a result of these being introduced via the reference group.

Resources are currently being explored for use by General Practitioners. In particular, CCDH (Victoria) and the NEPCP have had preliminary discussions with the local Primary Health Network (PHN) regarding the project. Further conversations will explore potential partnerships with a PHN to develop resources and training packages for GPs.

CareSearch (a national website providing palliative care information to family and professionals) was approached during the project to discuss incorporating the resource developed by the project, as well as updating the current information available on the website for people with intellectual disability, as well as staff, family and friends. An agreement has been reached to provide the resources as they are ready for distribution, and the LTUPCU will forward relevant and recent research articles and resources to be uploaded on the website. On completion of this task, CareSearch has agreed to promote the resources to the disability sector for a period of time, using the networks of the Reference Group (or newly formed Committee). The aim is to improve the visibility of the website and promote its value for the disability sector via networks.

## ✓ Outcomes Eleven, Twelve and Thirteen

- 11. Practice resources have been developed for use in residential services to support staff to provide, and residents to receive end-of-life care, and die at home.*
- 12. Through connections in the Reference Group with PHN, discussions that explore the development of resources to support General Practitioners will continue.*
- 13. An agreement with CareSearch has been reached to provide new resources and update disability end-of-life information for the website. A strategy to increase visibility and promote its value to the disability sector through partnerships and networks has been agreed upon.*

## Future Directions

As stated, the Project Reference Group has agreed to continue its partnered work beyond the funding provided by the North East Primacy Care Partnership. The group is meeting in September 2016 to discuss its ongoing state-wide advocacy, resource and advisory role, and how it links with existing initiatives in Victoria to strengthen the work. At this stage, the group is proposing that it becomes an ongoing Committee, with regular meetings scheduled,

alongside the capacity to respond to emerging issues that relate to the provision of end of life care to Victorians living with intellectual disability.

## ✓ Outcome Fourteen

*The Reference Group is transitioning to an ongoing Committee to attend to future directions, alongside the capacity to respond to emerging issues that relate to the provision of end-of-life care to Victorians living with intellectual disability.*

Future directions include:

- the suggestion from the research participants about mentoring house supervisors who are expecting their first home death, and the handing over of more routine work to allow the house supervisor more time to prepare for the death;
- the development of a resource for GPs to raise awareness of the needs of ageing or dying people with an intellectual disability; and
- the desire for Rosie (see research report) to have her grave marked by a headstone (preferably in the shape of a cappuccino).
- The group agreed to conduct a test case of the application of the NDIS at end-of-life for a resident receiving care in the group home. NEMA is the first region in the roll out of the NDIS and provides an opportunity to examine the interface with the NDIS in the context of end-of-life care.

## Summary

This project has produced multiple outcomes through partnership at state, regional and local level. The Reference Group intends to continue work together to advise on, advocate for and inform development of improved end-of-life care outcomes for people living with intellectual disability in Victoria. We expect to continue the partnerships created through regular committee meetings and to progress the future directions outlined in this report.

## Practice Resources (attachments)

### References

About the Disability Act 2006 Information Sheet (2007),

[http://www.dhs.vic.gov.au/\\_data/assets/pdf\\_file/0008/598940/disability\\_act\\_web\\_print\\_version.pdf](http://www.dhs.vic.gov.au/_data/assets/pdf_file/0008/598940/disability_act_web_print_version.pdf)

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