

Disability Health Promoting Palliative Care (HPPC) Framework: La Trobe University Palliative Care Unit



Aim: To build resilience in the Victorian disability sector, its partners and the wider community when encountering issues related to dying, death, loss & bereavement

Strategy: Public Health approaches that develop policy and programs **and** build organisational & community capacity in the disability sector so that people living in residential services with a life-threatening illness are cared for appropriately and die in their place of choice

The La Trobe University Palliative Care Unit (LTUPCU) aims to build capacity in the disability sector in relation to issues of dying, death, loss & bereavement through a Health Promotion Palliative Care (HPPC) Framework that incorporates a sustainable public health approach reflecting a social determinants understanding. It sets out to promote death and grief as a normal part of life through actions that challenge social norms, support healthy end of life planning, reduce fears and stigma and build resilience in the face of grief and loss. The Unit adopts an asset-based approach to guide the work, and uses capacity building principles, organisational and community development methods, advocacy and community participation which recognise that lasting change engages the community you are trying to support from the outset.

Reorient organisations	Develop skills	Strengthen action & advocacy	Create supportive environments	Health in All Policies (HiAP)
<p>Partner with palliative care services to review models of service provision. Services identify people with intellectual disability (PWID) as members of a vulnerable population with particular end of life needs to be considered in assessment & service provision.</p> <p>Policy, protocols & processes reflect this in service delivery</p>	<p>Deliver education & skill development in social approaches to end of life support for disability services staff & caregivers. Develop staff skills that provide social, emotional and spiritual support to PWID living with a life-limiting illness (LLI) in residential services.</p> <p>Reduce experiences of marginalised dying</p>	<p>Advocate for funding models and resources that support residents to receive end-of-life care in their home. Undertake cost benefit analysis of care provision in disability residential services compared with care provided in hospitals or palliative care units</p> <p>Map palliative care service provision & disability sector costs. LTUPCU Project</p>	<p>Work with organisations affiliated with disability services regarding end-of-life provision for residents and staff. Standard practices of the coroner's office, Victoria Police, funeral services, and day programs can undermine good end-of-life care practice for residents, co-residents, staff and families.</p> <p>Partnership Development</p>	<p>Combat death-denying health policies and attitudes that create barriers to dying well. Organisational policies and practices that view dying solely a medical event, not as a social event, result in inadequate end-of-life support for residents living in supported accommodation.</p> <p>Build healthy public end-of-life policy</p>
<p>Partner with the disability sector to build sustainable organisational capacity that support residents with end-of-life care needs. Guide the development & implementation of HPPC practices & protocols to support the sector to incorporate end of life support in service delivery.</p> <p>LTUPCU Consultancy & Research Projects</p>	<p>Promote supported end of life decision making for residents through the implementing Advance Care Planning processes suitable for people with mild or profound intellectual disability. Deliver training for staff in end of life planning & communication on death & dying.</p> <p>Deliver training for staff in end of life planning</p>	<p>Promote and advocate for the disability sector to take leadership in coordinating end of life care for their residents. Support & empower services to care for their residents using a social model of dying. Strengthen health services role in identifying deterioration early.</p> <p>Community Development model for sustainable change</p>	<p>Develop programs that provide concrete experiences for residents with intellectual disabilities to understand dying and death. Partnered programs with community organisations such as the arts, or local churches can assist PWID to understand the concept of death.</p> <p>Practical & concrete programs support PWID to understand the concept of death & dying</p>	<p>Create workplace bereavement policies to normalise and promote support for bereaved staff members, family and co-residents. Bereavement policies work to reduce social isolation in grief, promote healthy workplaces, improve staff and resident support and reduce stress & absenteeism.</p> <p>Specialised bereavement support for PWID (e.g. sign language)</p>
<p>Engage community organisations, services & community groups to increase resources for end-of-life support, including local government programs, acute sector, community hospital programs, GP's, community health and volunteers.</p> <p>Work with existing programs to incorporate end-of-life support in disability services</p>	<p>Identify community leaders or volunteers interested in end-of-life support for PWID. Build capabilities & skills in local volunteer programs to mobilise a volunteer or pastoral care workforce that has specific skills to support residents, staff and families in disability residential services.</p> <p>LTUPCU Project</p>	<p>Promote storytelling and legacy as important healing processes in bereavement. Develop creative arts projects that provide opportunities for PWID to participate in rituals of legacy and remembrance, and other creative practices that support healthy bereavement processes.</p> <p>Concrete activities are helpful for PWID</p>	<p>Work with the sector to shift the focus of care from self-determination and independence to quality of life care for the ageing population living in disability residential services. Early identification of deterioration in the aging residents will improve end-of-life support and care.</p> <p>Embed Palliative Approach</p>	<p>How do vulnerable and marginalised groups in our community experience end-of life? Address access inequities to acute and community health services that provide end of life support. Services develop policies and protocols that provide responsive and appropriate care to PWID. End-of-life services map & actively engage vulnerable populations in their region</p>