

Dying Well Community Panel

North Western Melbourne Primary Health Network

*What does dying well look like and
how can we help people achieve this?*

Community Panel Report

2 December 2018

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1 Introduction: the Dying Well Community Panel

NWMPHN invited 27 people from various backgrounds and within the North Western Melbourne Primary Health Network catchment area to come together over a period of two and a half days to explore the topic:

“What does dying well look like and how can we help people achieve this?”

Participants’ experiences and knowledge in this arena varied from professional to personal. The intent was to improve upon current practices in caring for people who are dying.

From discussions 14 recommendations were developed and refined.



2 Definition from the Panel: Dying well is ...

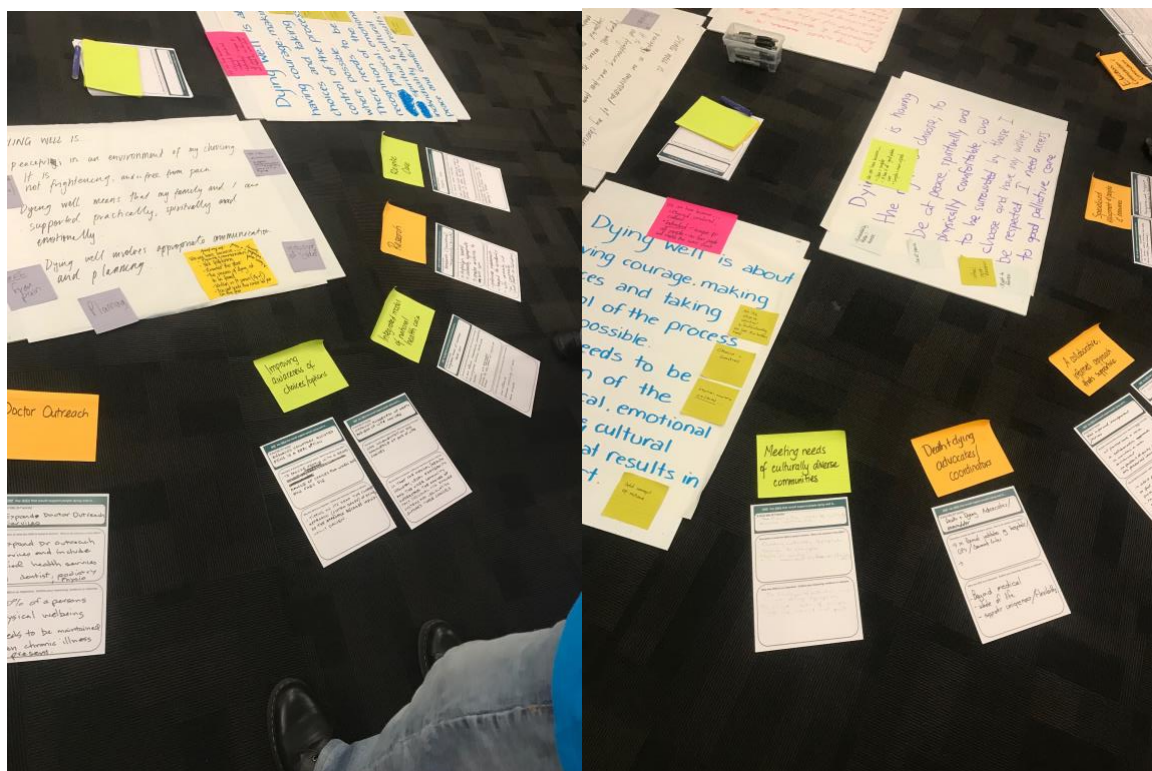
Dying well is an individual experience. The dying process impacts on the individual, their family and their social networks.

Dying well includes access to comprehensive information, and incorporates effective communication, and appropriate and integrated planning in order to make dying more peaceful and comfortable.

Dying well includes early access to and coordination of physical, medical, psychological, social, cultural and spiritual support to meet one's individual needs, choices and dignity.

Dying well entails maintaining the integrity of the dying individual's wishes.

The right to die well should be embedded in legislation, education, practice and service delivery.



3 Recommendations from the Panel

Majority Report

Recommendation Heading: 3.1 Access to high quality palliative care/palliative care packages.
Description: To allow people of all ages to have access to increased resources (specialised equipment, staff, drugs and care), available 24/7, in order to support their choices/quality of life wishes.
Rationale/Reasoning: People who want to die at home can do so with appropriate levels of skilled and hands-on support. Current palliative care services are too narrowly defined. Carers will be better supported in their roles.

Recommendation Heading: 3.2 Children and their rights
Description: To encourage and empower children under 18, where appropriate and in collaboration with their guardian(s)/primary carer(s) and professionals, to make their wishes known in a formal way, i.e., Advance Care Directive Allow children to choose an advocate they can work with to discuss fears and decision making.
Rationale/Reasoning: <ol style="list-style-type: none">1. Their special needs should be considered where there are no legal rights in place.2. Gives child and parents/guardian reassurance that the child's wishes are known and implemented.3. Encourages end of life conversations across the lifespan to clarify the needs and wants of the child.

Recommendation Heading: 3.3 Comprehensive model of palliative care services.

Description:

The palliative care model needs to be inclusive, equitable and accessible to individuals of all ages, cultures and religions, irrespective of economic circumstances.

It needs to be efficient, comprehensive, accessible, integrated, and timely in its delivery.

Rationale/Reasoning:

Provide continuity of care.

More reliable delivery of comprehensive palliative care.

Cost-effective use of available funds.

Recommendation Heading:**3.4 Provision of respite care in and out of the home on a needs basis****Description:**

Respite care refers to either in-home or out-of-home care provided by respite care workers to temporarily relieve the primary carer (e.g. family member) from their caring responsibilities and allow them to have a break and undertake other activities. Some in-patient hospice services may provide in-patient hospice admission for up to 2 weeks. Some local councils may offer up to 3 hours/week of respite care at home. We are asking that respite care becomes a part of a suite of integrated care services offered by palliative care programs. Respite care should be provided on an as-needs basis to those who want it.

Provide help to carers to continue to provide ongoing good care in the home environment.

Maintain the quality of life for both the dying person and carers.

Relieve carers' stress and burden by ensuring that respite care services cover practical and hands-on support activities at home. Prevent carer burnout by providing relief from duties on a needs basis.

Respite care services, especially those provided at home, should be sensitive to and account for people's background, personal circumstances and needs (including disability). We would like to ensure that care is provided free of judgment, discrimination and anything else that might harm the person and their family.

Make dying at home possible for people regardless of their socio-economic status.

On admission to palliative services, the dying person and their carers are provided with information about what respite care means and how to access it.

Rationale/Reasoning:

Currently, there is inadequate at-home respite care. At the moment, you can request a charitable or palliative care service to provide some volunteer support (i.e., limited companionship). More hands-on respite care that is factored into integrated, funded care packages is required.

Preventing carer burnout may also prevent unnecessary hospitalisation or placement in aged care.

Help make dying at home a better experience for the family member who is dying and for carers.

Enable family relationships and friendships to continue until death.

Recommendation Heading:**3.5 Individualised choices for death and dying should not be restricted.****Description:**

To provide people a broad range of choices for when and how they die.

Rationale/Reasoning:

1. The current choices are narrow. Voluntary assisted dying is not a real option in 2019.
2. It is challenging the current approach to dying so that it becomes driven by the individual.
3. It is respecting and responding to individual wishes.

Recommendation Heading:**3.6 Research and continuous improvement****Description:**

Ongoing development of a national evidence database, including documentation of patient and carer experiences, community involvement and feedback.

Rationale/Reasoning:

Evidence and documentation of experiences can drive systems improvement.

Empowerment - community collaboration provides opportunity for community participation in systems improvement.

Comprehensive and diverse scope - different aspects of dying well / palliative care / etc.

Recommendation Heading:

3.7 Funded End Of Life advocates/ coordinators

Description:

Provide the option for a suitably trained person to be available as a continuous interface between the health team and patient/carers to support all relevant End Of Life services for the individual needs of the person.

This should last from initial contact through to post-death and the bereavement process.

Rationale/Reasoning:

1. This should optimise continuity of care and communication with the person and their family.
2. This should allow the person/family/carer to access services that fit their individual needs.
3. This should hopefully give peace of mind to the person and their family.

Recommendation Heading:

3.8 Access to medication

Description:

Reduce the number of visits that patients and families need to make to GP for prescriptions.

Rationale/Reasoning:

To reduce associated stress on families/carers.

Reduce cost to the tax payer.

Reduces time carer is away from patient

Recommendation Heading:

3.9 Menu for end of life care options.

Description:

'I didn't know I could do that!' results in unnecessary distress and regret.

Knowing all of the non-pharmaceutical treatments and options that are available at end of life will ensure that you can tailor your needs, interests and choices to enable and support your end of life experience. A few of these complimentary services on the menu may include: recreational, beauty, massage, art and music therapies, animal companionship/therapy, podiatry, dental care, optometry, and physio and occupational therapy.

Not knowing the menu options available means that you may not be aware of the possible choices, and this can result in lost opportunities for holistic care.

If key points of contact (GP's, pharmacists, social workers etc) for the patient were able to provide a menu of flexible and professional services available, a patient could tick what they might be interested in or what they would like to know more information about. The end of life coordinator/advocate/family, or even the patient themselves, may be able to access these accredited services.

Accreditation could take the form of having professionals from these complementary services (eg: hairdresser) provided with additional formalised training and orientation modules, could allow them to more confidently, safely and effectively work with the dying and their families.

Rationale/Reasoning:

Dying well is more than physical, medical or pharmaceutical. To die well also needs to address the social, cultural, emotional and spiritual needs of the individual person. Knowing what your options of support are, will enable you to access complimentary services which promotes agency and empowerment over end of life experience.

Recommendation Heading:

3.10 Education, communication, conversations about 'dying' and End of Life choices

Description:

- Investing in education of both community and health professionals regarding planning of the individual process of 'dying well'
- Open conversation needs to start early at schools, community and continue through life to help people feel more comfortable to discuss topic of death.
- Include this topic into the curriculum of health and education professionals training taking into consideration cultural and diversity aspects
- Ongoing professional development and training for those providing end of life care
- Provision of education and training of family/ carers in the community in tasks to provide EOL care
 - Education to both professionals and individuals about advance care planning to enable planning to commence early
- EOL education to be included in the curriculum and induction of medical and allied health students

Rationale/Reasoning:

Conversations and education can normalise death to enable the person to plan and die well
Reduces anxiety, stress and fear of the unknown when facing life crises
Work toward a plan for what 'dying well' looks like to the each individual

Recommendation Heading:

3.11 Cultural and situational needs

Description:

The intent of this section is to ensure that no marginalised group is disadvantaged by their socioeconomic position, geographical location, personal demographic, being socially isolated or their cultural background. Ensure services are sustainable to provide continuity of care.

Rationale/Reasoning:

Consider factors that may impact on marginalised groups, with particular focus on individuals in remote areas. Marginalised groups that need to be considered can include: cultural groups, disability, socioeconomic, remoteness, access to services, experience of discrimination and family circumstances.

Specific challenges of marginalised groups need to be addressed and catered for.

To ensure marginalised groups have equal access to services, and their challenges are recognised and catered for.

Recommendation Heading:

3.12 Recruitment and training of specialised staff

Description:

To ensure all relevant staff have the knowledge and skills required to care for the dying person and their support persons, as general staff don't have this knowledge

Provide education and support to GPs and outreach medical staff to upskill in the area of palliative care.

To allow dying individuals access to all allied health services within their homes and care facilities.

Experienced staff include nurses, doctors, spiritual carers, bereavement counsellors, counsellors, social workers and allied health workers.

Rationale/Reasoning:

Specialised staff have the ability to assess patients needs and provide care based on evidence based practice.

To support GPs and outreach medical staff with the skills required to serve their dying patients effectively.

All allied health services (podiatry, dentistry, dietetics, social workers, physio, occupational therapists, spiritual care counselling, recreational therapists) should be available to all patients - we are all living until we die.

Recommendation Heading:

3.13 Making the *implementation* of Advance Care Plans legally binding

Description:

Create a national database for the storage of Advance Care Plans, linked to My Gov Record / Medicare / My Health Record.

Broaden the scope of Advance Care Directives to include people's values, 'spiritual' (cultural, social and emotional) beliefs and post death instructions as well as medical treatment wishes.

Implementation of Advance Care Directives is mandatory and there are regular audits to make sure that people's wishes are being followed.

Rationale/Reasoning:

To ensure people's wishes and preferences are implemented and legally binding.

To ensure people are in control of their death/end of life choices.

To ensure that dying well is more than just a series of medical processes.

Recommendation Heading:

3.14 Financially sustainable person centred care

Description:

Irrespective of where care is delivered, all stakeholders, in collaboration with a multidisciplinary team, receive the highest quality care necessary to meet an individual's expectation of 'dying well'.

Rationale/Reasoning:

Financial constraints at either an individual or institutional level should not dictate how someone dies.

Important to have a co-ordinated funding stream to ensure services are practical and targeted to meet the needs of all stakeholders.

Funding allocation is important to educate and support specialised staff and volunteers, thus ensuring sustainability and continuity of services.

Recommendation Heading:

3.15 Aboriginal & Torres Strait Islander (A & TSI) people have the right to die well with dignity and cultural respect

Description:

Have A & TSI peoples, lead by Elders, address cultural sensitivities around dying well and have them participate so they can develop a culturally appropriate way of dying, which respects the rich cultural traditions and diversity for each A & TSI person. This includes rituals such as burials and going home to 'country.' Also important is creating greater public awareness in the mainstream community.

Rationale/Reasoning:

- A & TSI traditions are not respected or understood in the wider community, nor is the many traumas associated with the takeover of this country now known as Australia
- A & TSI people are the most marginalised people in society, which has lead to low levels of housing, health, education and employment, which has seen greater poverty in A & TSI Communities.
- As addictions such as drug and alcohol dependence and gambling have infiltrated A & TSI Communities, these have significantly affected their health outcomes leading to reduced rates of longevity.

Minority Report

Recommendation Heading:

3.16 Access to specialised professional advice

Description:

To protect the dying from financial mis-management with regard to aged care accommodation. Provide professional advice when compiling the advance care plan.

Rationale/Reasoning:

Access to professional advice in regards to the legal ramification of aged care accommodation, Access to qualified medical person when compiling advances care plan.

“The little things are the BIG things”

(Community Panel members)

4 Action from NWMPHN

Representatives from the panel attended a meeting with NWMPHN Executive to present the Panel’s recommendations, to assist in understanding and decision making for the Executive.

Following further exploration and assessment of the Community Panel Report, NWMPHN prioritised six of the Panel’s recommendations.

- Item 12: Recruitment and training of specialised staff
- Item 10: Education, communication, conversations about ‘dying’ and End of Life choices
- Item 9: Menu for end of life care options
- Item 8: Access to medication
- Item 1: Access to high quality palliative care/palliative care packages
- Item 15: Aboriginal and Torres Strait Islander (ATSI) people have the right to die well with dignity and cultural respect

NWMPHN will collaborate with subject matter experts and community to plan and deliver activity that responds to each of these six recommendations.

Appendix

1. Video for Dying Well Community Panel forum:

https://nwmpnhn.org.au/news/dying-well-look-like/?utm_medium=email&utm_campaign=NWMPHN%20Network%20News%2026%20February%202019&utm_content=NWMPHN%20Network%20News%2026%20February%202019+CID_e661a007d40a9c5a97f27a7edd08a60d&utm_source=Network%20News&utm_term=our%20website

https://www.youtube.com/watch?v=vux9gXHu_1Q&feature=youtu.be

2. Background paper for community panel consultation on ‘What does dying well look and how can we help people achieve this?’ (13 November 2018):



Background paper
EOL comm panel draf