

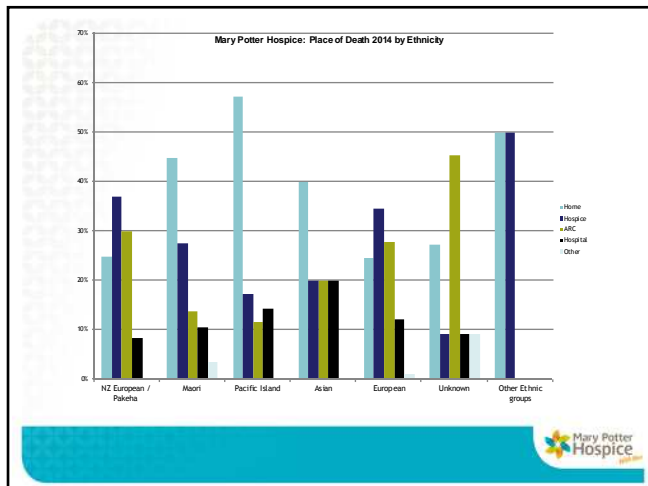


Home Deaths. How Are We Doing?

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Dying at home for Maori

- <https://www.youtube.com/watch?v=G9zXJOnRuEI>
- Stella's story - 21.13 - 23.57 (2.44 minutes)



Experiences and Preferences

- Patient centred care
- Sometimes culturally safe
- Space for collective decision making is challenging
- Shared by multiple unfamiliar faces
- Clinically competent
- Some social work supports
- Driven by mainstream western health approach
- Whanau centred care
- Culturally safe and appropriate
- Awareness of wairua and cultural ways of being
- Shared by familiar faces
- Clinically competent
- Earlier relationship and different bereavement care
- Greater need for social support and advocacy e.g. WINZ, HNZ
- Greater Maori flavour



'No matter what the cost'

Findings: Cost of care giving is significant.

- Results in debt or bankruptcy
- Direct costs (transport, food and medications)
- Indirect costs (employment, cultural needs, own health)

Conclusion: Research is needed

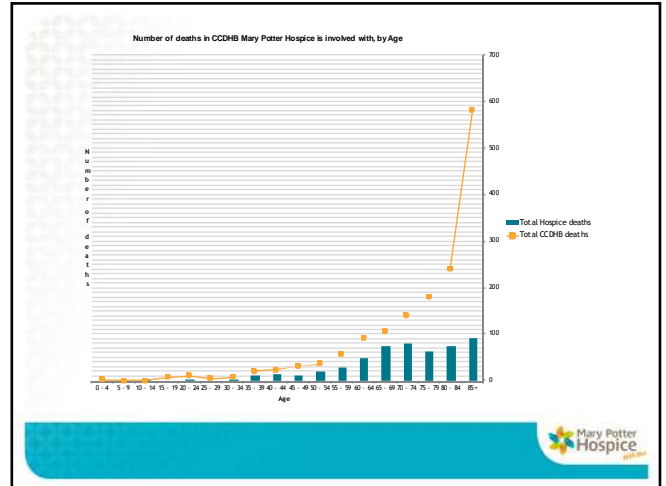
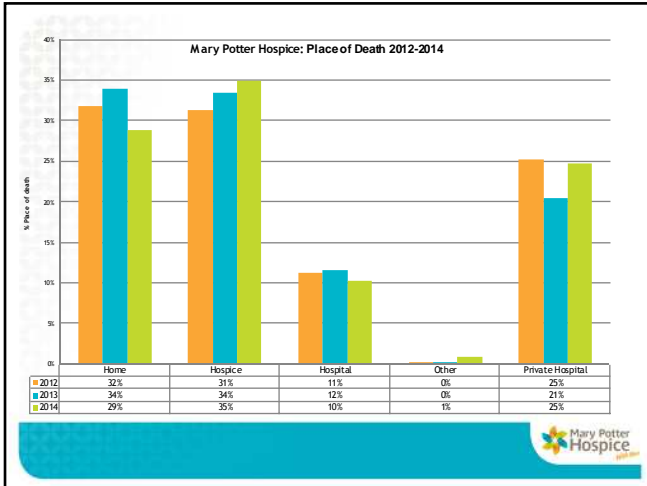
- To quantify contribution of whanau caregiving
- Particularly important given shift to move palliative care provision to the community



Preferred Place of Death

- Research worldwide identifies home as people's preferred place of death
- In the UK home deaths have fallen from 60% in the 1960's to 18% in 2008.
- Throughout EEC countries 65 - 80% of people identify home as PPoD but only 21% achieve this.





Rural vs Urban

- Patients living in rural communities are more likely to achieve home death when identified as PPOD. (*Preferred place of death*)
- Rural communities have a different “culture”.
- Families are more likely to be available as carers.
- Institutional care is less acceptable.

- Urban families and whanau are often wider spread.
- Expectation is of full time work for all family members.
- Fewer family resources.
- Institutionalised care is more acceptable to families?
- Health professionals are more inclined to promote institutionalised care for EOL?

Case Study 1

56 yr woman. Married to an arborist. Mixed family 5 adult children. Home in various stages of being renovated.

Nursing background. No other health professionals in family.

Pancreatic cancer, EOLC at home.

Carers: husband, son (28) District Nurses, GP.

Distance to nearest hospital 45 minutes.
No hospice in-patient unit

Case Study 2

Farmer, 62 yrs. Married, 3 children. Oldest son & family working on the farm.

Metastatic bowel cancer.

Continued to work on the farm until final few weeks.

No health professionals in family.

Cared for by wife and sometimes daughter.

Distance to nearest hospital 2 hours



“The closeness- lying with him when he’s in pain, trying to comfort him- I get a lot out of that, even though it was almost killing me watching him in pain.”



Hudson 2004

What influences the outcomes of a home death?

- Early discussion of Preferred Place of Death
- Availability of carers
- Availability of health professional support
- Planning
- Education & support for carers
- Attitude of health professionals
- After hours support

- Great GP's available for A/H support and Home Visits
- Assessment of environmental needs
- Good communication
- Identify clear expectations and resources early.
- Access to “Time out”
- Understanding of the “how to” of symptom control



Looking to the Future

- 24 hour Community specialist nurse cover.
- Carer Education programme.
- PC awareness campaign for Maori
- Maori workforce development
- Community Volunteers in the home

Looking to the Future

- Closer GP interface
- Addressing health professionals attitudes.
- Education of other specialist services - Renal/ Cardiac/ Respiratory.
- Interagency sharing & prioritising WINZ HNZ

Dreams

- Benefit for carers
- Job protection and carer leave
- Greater patient autonomy with palliative funding
- 24 hour support at home - quick response time



The Baby Boomers may change the community.
We will be the volunteer army of the future

If we don't dream nothing will change



Waiata - Ano te Pai

Once again its beautiful
To be at this hui
For the younger siblings, and the older siblings
Bringing forth collective love



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