

### Palliative care

Palliative care is care for people of all ages with a life-limiting condition.

---

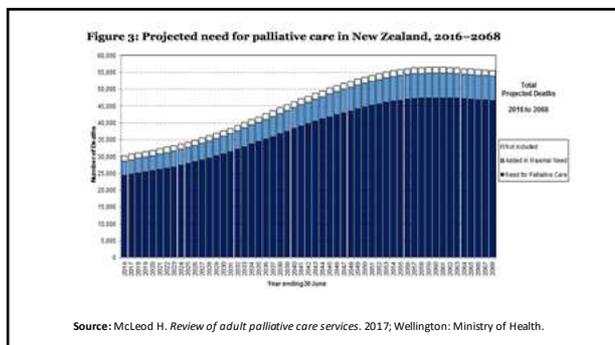
No matter who we are, no matter what our background, we all eventually face death and dying. Palliative and end of life care provides people with humane and dignified support and services as they face a life limiting condition. This care is essential.

Palliative care in New Zealand aims to:

- optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs
- support the individual's family, whānau and other caregivers where needed into bereavement.

“Grow the capability of family carers and communities”

### Family carers are the foundation of the palliative care workforce



Family members are increasingly being asked to perform complex tasks similar to those carried out by paid health or social service providers, often at great cost to their own well-being and great benefit to their relatives and society as a whole.

Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: prevalence, health effects, and support strategies. *The American journal of geriatric psychiatry*, 12(3), 240-249.



People are interconnected and their health is too.

Nicholas Christakis

What is "very important" to you at the end of life? (147 Māori aged over 80 years)



What is "very important" to you at the end of life? (291 non-Māori aged over 85 years)



We are the shadows in the system

Ros Cooper, ex-palliative carer



#hello my name is...

## Outline

- ① The work of family and whānau carers
- ② The costs of caring
- ③ Three routes to better support



## ① The work of family and whānau carers



Family carers spend on average 69 hours a week caring in the last three months of someone's life.

Rowland, C., Hanratty, B., Pilling, M., van den Berg, B., & Grande, G. (2017). The contributions of family care-givers at end of life: A national post-bereavement census survey of cancer carers' hours of care and expenditures. *Palliative medicine*, 31(4), 346-355.

Most do this in addition to full time paid work.

Unpaid carers contribute \$10.8 billion or 5% of New Zealand's GDP.

The economic value and impacts of informal care in New Zealand. Infometrics for Carers NZ and the NZ Carers Alliance, 2013.

At the end of life, one-fifth to one-third of the overall costs of caring for people fall on informal caregivers.

Round, J., Jones, L., & Morris, S. (2015). Estimating the cost of caring for people with cancer at the end of life: A modelling study. *Palliative Medicine*, 0269216315595203.

Having a well supported and informed family carer also reduces unplanned use of statutory health services. With resultant economic savings to the health system.

For example, unplanned hospitalisations at the end of life are often related to family ability 'to cope'.

Gott, M., Frey, R., Robinson, J., Boyd, M., O'Callaghan, A., Richards, N., & Snow, B. (2013). The nature of, and reasons for, inappropriate hospitalisations among patients with palliative care needs: A qualitative exploration of the views of generalist palliative care providers. *Palliative Medicine*, 27(8), 747-756.

Dying at home is associated with having good social support from family carers.

Gomes, B., & Higginson, I. J. (2006). Factors influencing death at home in terminally ill patients with cancer: systematic review. *Bmj*, 332(7540), 515-521.

## Te Pakeketanga: Living and Dying in Advanced Age



## Methods

58 interviews with the carers of 52 people (20 Māori & 32 non-Māori) who had been enrolled in the LiLACS NZ study and nominated a whānau or family member to be interviewed after their death.

Task	Definition	Example
Personal care	Physical care involving the body	Toilet
General care	Domestic care	Cooking
Securing and managing resources	Arranging help, services, equipment, ongoing monitoring	Arrange medical alarm
Navigation	Co-ordinating care	Sharing information between care settings
Emotional support	Emotion work, being present, support of spiritual need, <del>holding</del> <del>holding</del> while dying	Hold hand while dying
Advocacy	Balancing different needs, attitudes and intentions (of person receiving care, other family members, professionals)	Protect from unwanted medical care
Decision making	Making medical decisions, soliciting and sorting advice	Discuss care treatment plan
Nursing care	Management of prescribed medications/nursing tasks	Inject morphine
Financial management	Handling of finances, legal matters	Paying bills
Accompanying	Companionship	Drive to visit friends

## Achieving each task involves...



Wiles, Gott et al. in preparation



### What carers want

- ① Recognition
- ② Involvement
- ③ Support

### What carers offer

- ① Expertise
- ② Unique information
- ③ Commitment and time

### ② The costs of caring

### Mental health

Approximately half of carers of people with an advanced life limiting conditions meet DSM criteria for mental health disorders.

Rumpold, T., Schur, S., Amering, M., Kirchheiner, K., Masel, E. K., Watzke, H., & Schrank, B. (2016). Informal caregivers of advanced-stage cancer patients. *Supportive Care in Cancer*, 24(5), 1975-1982.  
Miravittles, M., Peña-Longobardo, L. M., Oliva-Moreno, J., & Hidalgo-Vega, A. (2015). Caregivers' burden in patients with COPD. *International journal of chronic obstructive pulmonary disease*, 10, 347.

### Physical health & mortality

Carers who report 'caregiver strain' have a mortality risk which is 63% higher than that of non-caregivers.

R. Schulz, S.R. Beach. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study *Journal of the American Medical Association*, 282 (23) (1999), pp. 2215-2219



<p><small>Review Article</small></p> <p><b>Gender and family caregiving at the end-of-life in the context of old age: A systematic review</b></p>	 <p><small>Journal of Medical Ethics 2015, Vol. 30(1), 1-10 © The Author(s) 2014 Reprints and permissions: sagepub.com/journalsPermissions.nav DOI: 10.1177/0962280214263827 jme.sagepub.com</small></p> <p><small>SAGE</small></p>	<p><b>Women caregivers experience a greater degree of mental and physical strain than their male counterparts. This is linked to societal expectations that women should provide a greater degree of care at end of life for family members.</b></p>
---	--	--

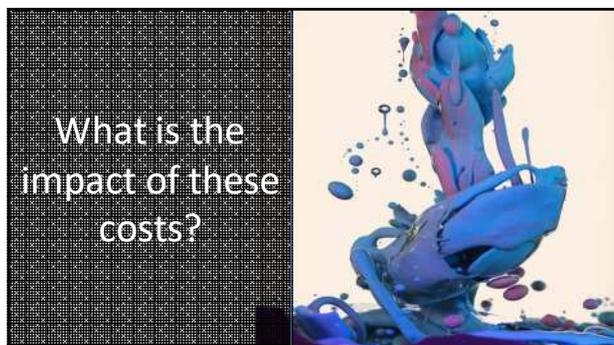
## Financial security

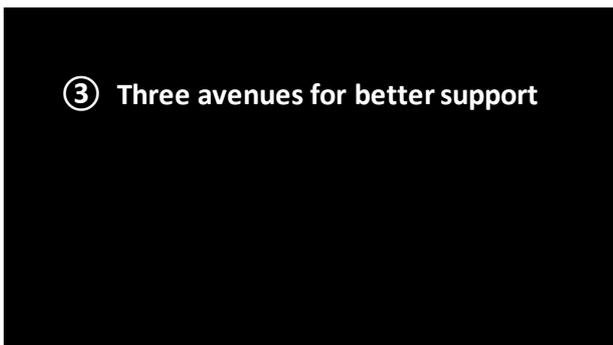
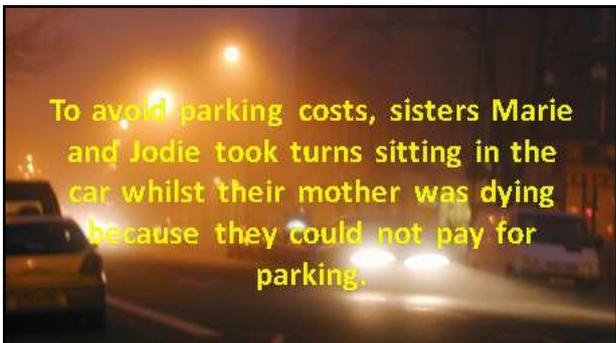
Women who are family caregivers are 2.5 times more likely than non-caregivers to live in poverty and are 5 times more likely to receive benefits.

Donato, K., & Wakabayashi, C. (2005). Women caregivers more likely to face poverty. Presented at American Sociological Association, San Francisco. Retrieved January 10, 2007, from [www.media.rice.edu/media/NewsBot.asp?MODE=VIEW&ID=5498&SnID=2](http://www.media.rice.edu/media/NewsBot.asp?MODE=VIEW&ID=5498&SnID=2).



<p><small>Original Article</small></p> <p><b>'No matter what the cost': A qualitative study of the financial costs faced by family and whānau caregivers within a palliative care context</b></p> <p><b>Merryn Gott, Ruth Allen, Tess Pooko-Macwell, Clare Gardiner and Jackie Robinson</b></p>	 <p><small>Journal of Medical Ethics 2015, Vol. 30(1), 1-10 © The Author(s) 2014 Reprints and permissions: sagepub.com/journalsPermissions.nav DOI: 10.1177/0962280214263827 jme.sagepub.com</small></p> <p><small>SAGE</small></p>	<p><b>Abstract</b></p> <p><b>Background:</b> There has been significant attention paid in recent years to the economic costs of health care provision for people with palliative care needs. However, little is known about the costs incurred by family caregivers who typically provide the bulk of care for people at the end of life.</p> <p><b>Aims:</b> To explore the nature and range of financial costs incurred by family caregivers within a palliative care context.</p> <p><b>Design:</b> In-depth qualitative interviews were conducted with 30 family/caregivers who were currently caring for someone with a life-limiting illness or had done so within the preceding year. Narrative analysis was used to identify impacts and costs at the personal, interpersonal, organisational and structural levels.</p> <p><b>Setting:</b> Auckland, New Zealand.</p> <p><b>Findings:</b> Costs of ongoing care (equipment for participants, needed to deliver care) were high. A range of other (transport, food and medication) and indirect costs (related to employment, cultural needs and own health) were reported. A multi-level qualitative analysis revealed how costs impacted on a number of areas (personal, interpersonal, organisational and structural). The palliative care context increased costs, as meeting needs were prioritised over care. In addition, support from statutory services provided to some degree of financial support was limited.</p> <p><b>Conclusions:</b> Families incur significant financial costs when caring for someone at the end of life. Research is now needed to quantify the financial contribution of family and whānau caregiving within a palliative care context, particularly given shortages in many countries as well as how palliative care provision has community settings.</p>
---	---	--





**Why are Human Resource (HR) policies important? About the Compassionate Care Benefit (CCB)**

According to the Government of Canada, compassionate care benefits are Employment Insurance (EI) benefits paid to people who have to be away from work temporarily to provide care or support to a family member who is gravely ill and who has a significant risk of death within 26 weeks (six months). A maximum of 26 weeks of compassionate care benefits may be paid to eligible people.

It is a very stressful and difficult time when a loved one is dying and/or near death. The financial security of an employee's family may be jeopardized while caring for a gravely ill family member.

The Government of Canada has extended the current CCB from 6 weeks to 26 weeks so that employees do not have to choose between keeping their job and caring for their family. It is important to note that provincial labour laws are in need of updating.

It gave me some sense of security in terms of - at least there's one thing, from a financial perspective, in my life that I don't have to worry so much about...so I could focus on my mom.

Williams, A. M., Eby, J. A., Crooks, V. A., Stajduhar, K., Giesbrecht, M., Vuksan, M., ... & Allan, D. (2011). Canada's Compassionate Care Benefit: Is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care? *BMC Public Health*, 11(1), 335.

**What makes a Canadian Compassionate Company (CCC)?**

The Canadian Hospice Palliative Care Association and its Champion's Council will award the designation of a CCC if your company meets at least three out of five of the following criteria:

1. Your company has a HR policy that lays out a *Compassionate Care Leave Benefit (CCLB)* endorsing the job protected family medical Employment Insurance benefit currently at 26 weeks.
2. Your employees' jobs are protected while they are off on the CCLB program.
3. Compassionate Care leave could provide employees with income top-up of benefits over and above the job protected family medical EI benefits leave offered through the provinces and the Federal EI program.
4. Your company has a caregiver accommodation policy that allows for support and flexibility within economic reason.
5. Your company will promote Advance Care Planning (ACP) using resources and tools at [www.advancecareplanning.ca](http://www.advancecareplanning.ca) or create their own materials.

## 2. Health service interventions

**Carer Support Needs Assessment Tool (CSNAT)** Identifying and addressing the support needs of family carers



Home Resources Training Package Current users Latest news Events Contact us FAQs Useful links

**The CSNAT**

**CSNAT** Carer Support Needs Assessment Tool

<http://csnat.org/>

Compared with controls, intervention carers had significantly lower levels of early grief, better psychological and physical health, were more likely to feel the place of death was right, and patients were more likely to die at home.

Grande, G. E., Austin, L., Ewing, G., O'leary, N., & Roberts, C. (2017). Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. *BMJ supportive & palliative care*, 7(3), 326-334.

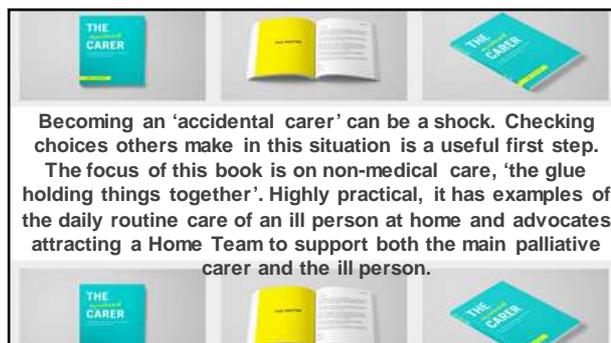
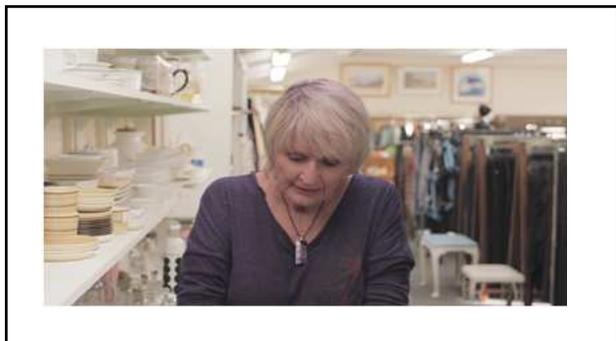


A public health approach to palliative care views the community as an equal partner in the long and complex task of providing quality health care at the end of life. Just as health, according to WHO, is 'everyone's responsibility' so too is death, dying, loss and care.

<http://www.phpci.info/public-health-approach/>



In the Pakeketanga study carers identified a key role for their communities in reducing social isolation and providing respite.



Home Teams were the common central thread uniting the experiences of the diverse family groups highlighted in my book. All five of us extended our family group into a 'Home Team', albeit in slightly different ways.



**The Whānau**

'Coming together is just what we've always done - coming together and making it work'.

Tane, who cared for his Nan.

## The Clan

'Jane and I realised we needed to call on as much support as possible from The Clan (our lesbian community). Jane was facing her death, and I had to face the fact that I was going to lose her, my life partner, lover and best friend for 25 years. It felt enormous. We knew we had to reach out.'

Pleasance, who cared for her partner.

## Question:

Could attracting a Home Team of family, friends and others become The Usual Way to approach the situation of a person living at home with a life limiting diagnosis and those who care for them? Could it be advocated? And support to do this provided by the community?

From accidental caring and research to community activism for change.



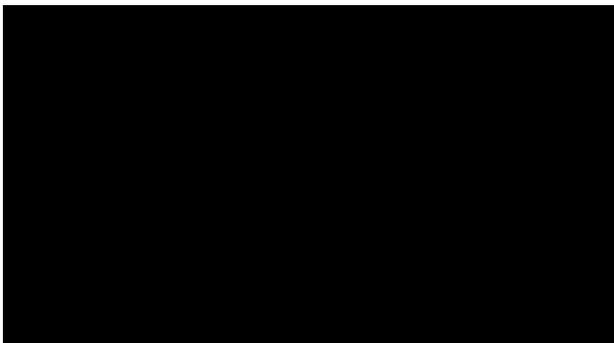
## Another example....



Led by Ofa Dewes and Lisa Williams

- **Aims:** to conduct a participatory action-research project in collaboration with Pacific Island family caregivers to develop new caregiving resources.
- **Methods:** focus groups and workshops.

- **Participants wanted to:**
  - raise awareness within their community of the work of family caregivers
  - use music as a medium for expressing their messages
  - highlight the wider contributions of family carers to their communities



**What I've argued.....**

Carers are a key resource within palliative care whose potential is not being realised. Supporting carers will not only improve their wellbeing, but that of the person with palliative care needs. Ultimately, given the exponential rise in palliative care need predicted in New Zealand, we can't afford NOT to support carers. This support should be provided at a structural level, as well as by health services and communities themselves.

**One response to this argument...**

At St Christopher's, we put our volunteers in a 'volunteer-shaped box'. Most are ex-carers and have significant experience, and expertise, in palliative care. We must use this resource more wisely.

Heather Richardson, CEO, St Christopher's Hospice



Here is a link to the digital resources referred to during the conference presentation:

<http://www.teararesearchgroup.org>



