

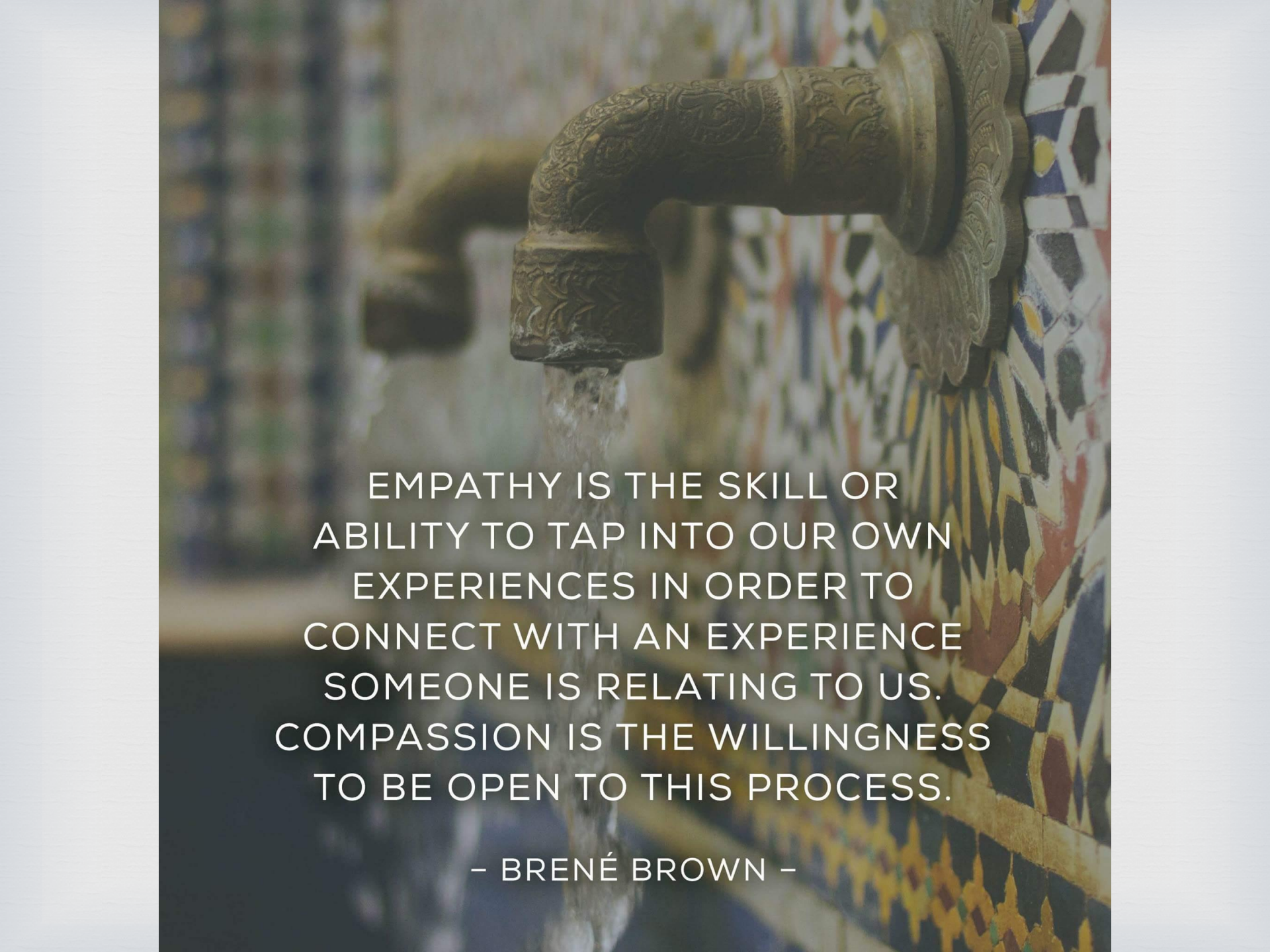


Neonatal Palliative Care: NZ Perspective



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Starship Child Health





EMPATHY IS THE SKILL OR
ABILITY TO TAP INTO OUR OWN
EXPERIENCES IN ORDER TO
CONNECT WITH AN EXPERIENCE
SOMEONE IS RELATING TO US.
COMPASSION IS THE WILLINGNESS
TO BE OPEN TO THIS PROCESS.

– BRENÉ BROWN –

Palliative Care in the NICU

☞ Overview Paediatric Palliative
Care

☞ Suffering requiring
Interventions

☞ Suffering requiring care
coordination

☞ Suffering requiring
communication

Definition: Paediatric Palliative Care



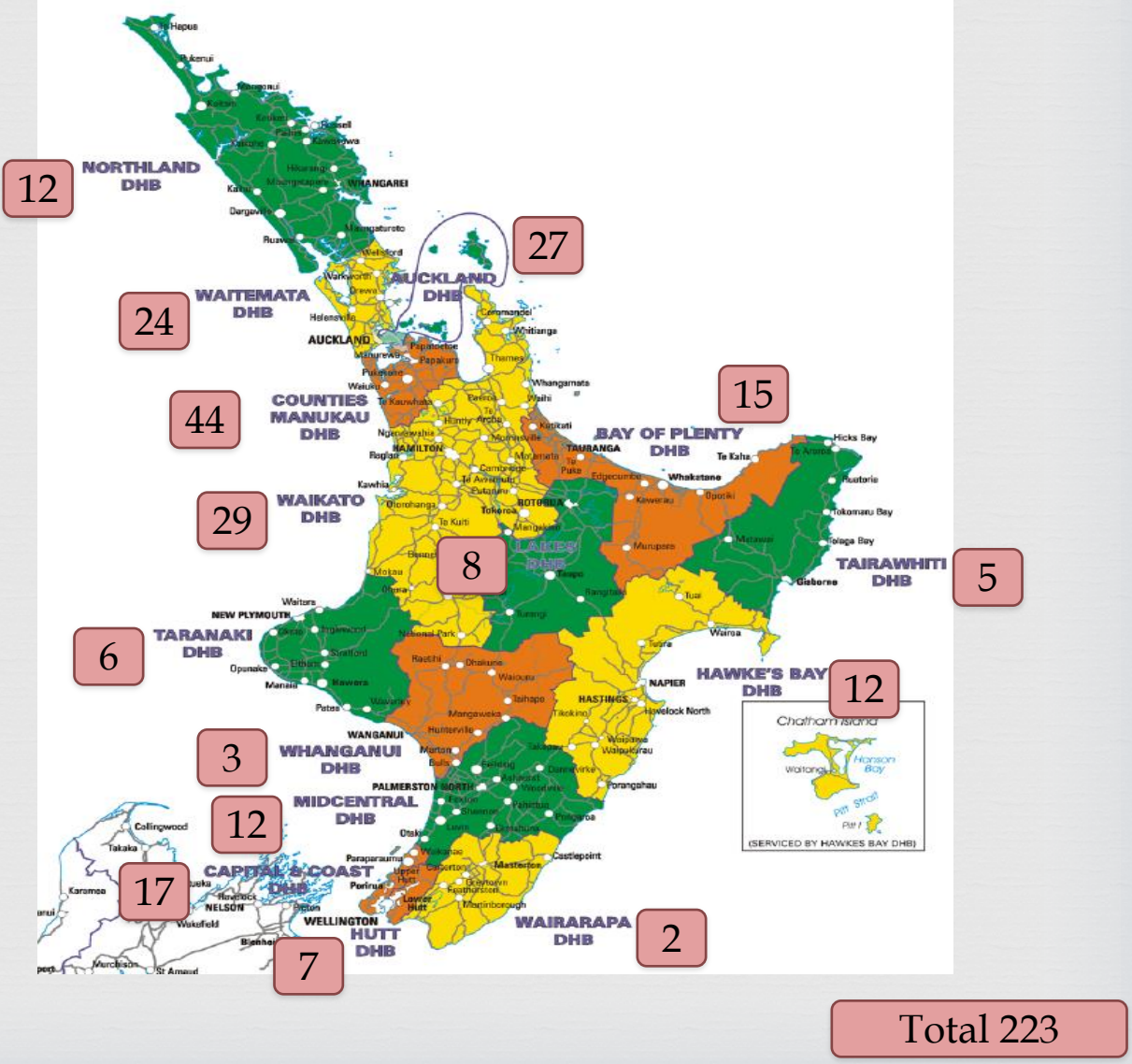
An approach to care covering physical, emotional, social, cultural and spiritual support. Focuses on improving quality of life for the infant,* their family members or carers, and includes managing distressing symptoms, providing respite care, and support with death and bereavement.

∞ NICE guideline [NG61] Published date: December 2016

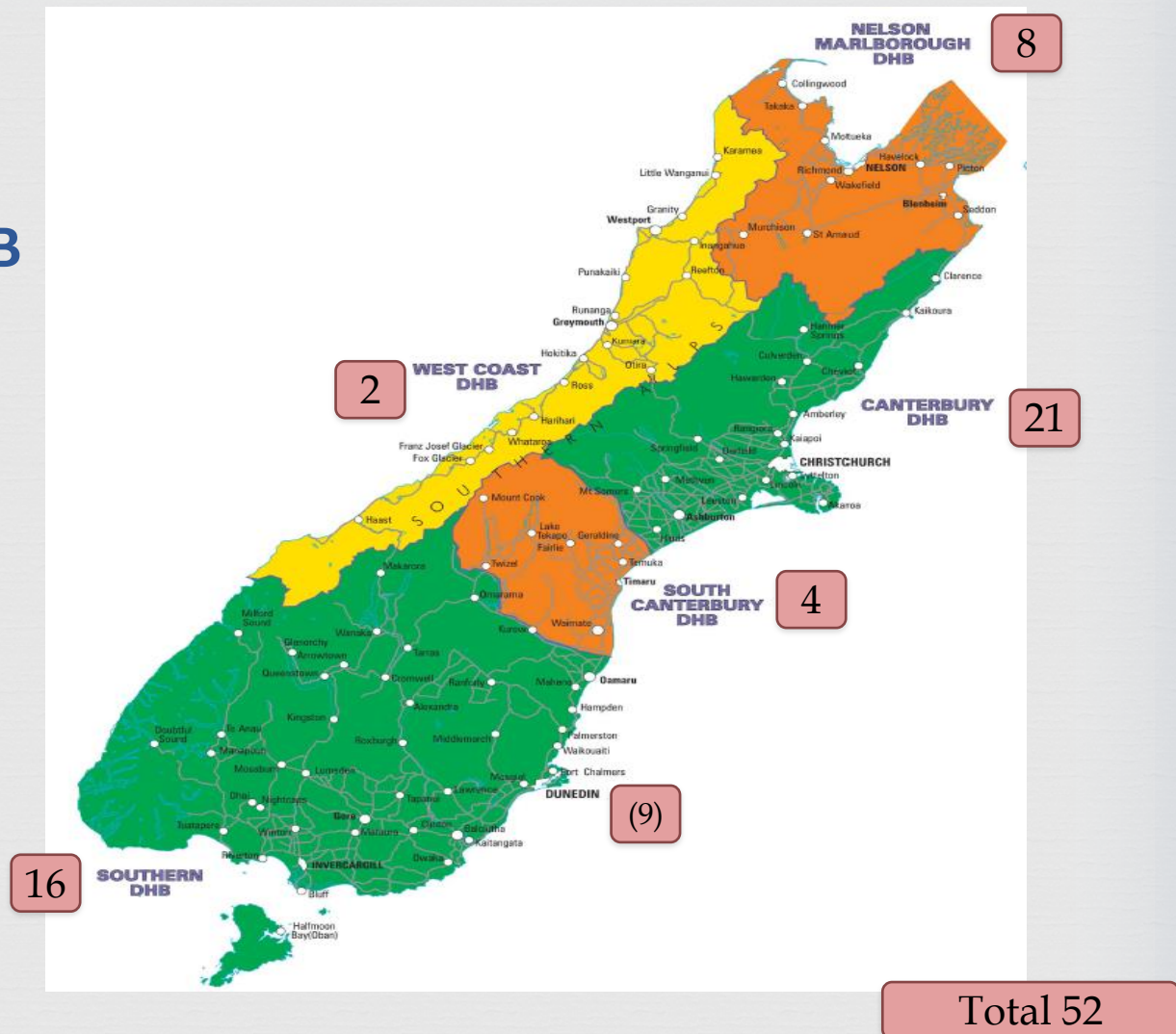
∞ <https://www.nice.org.uk/guidance/ng61>

* child and adolescent

Projected deaths 0-19 years of age where PC would be of benefit – 2011 population by DHB Region

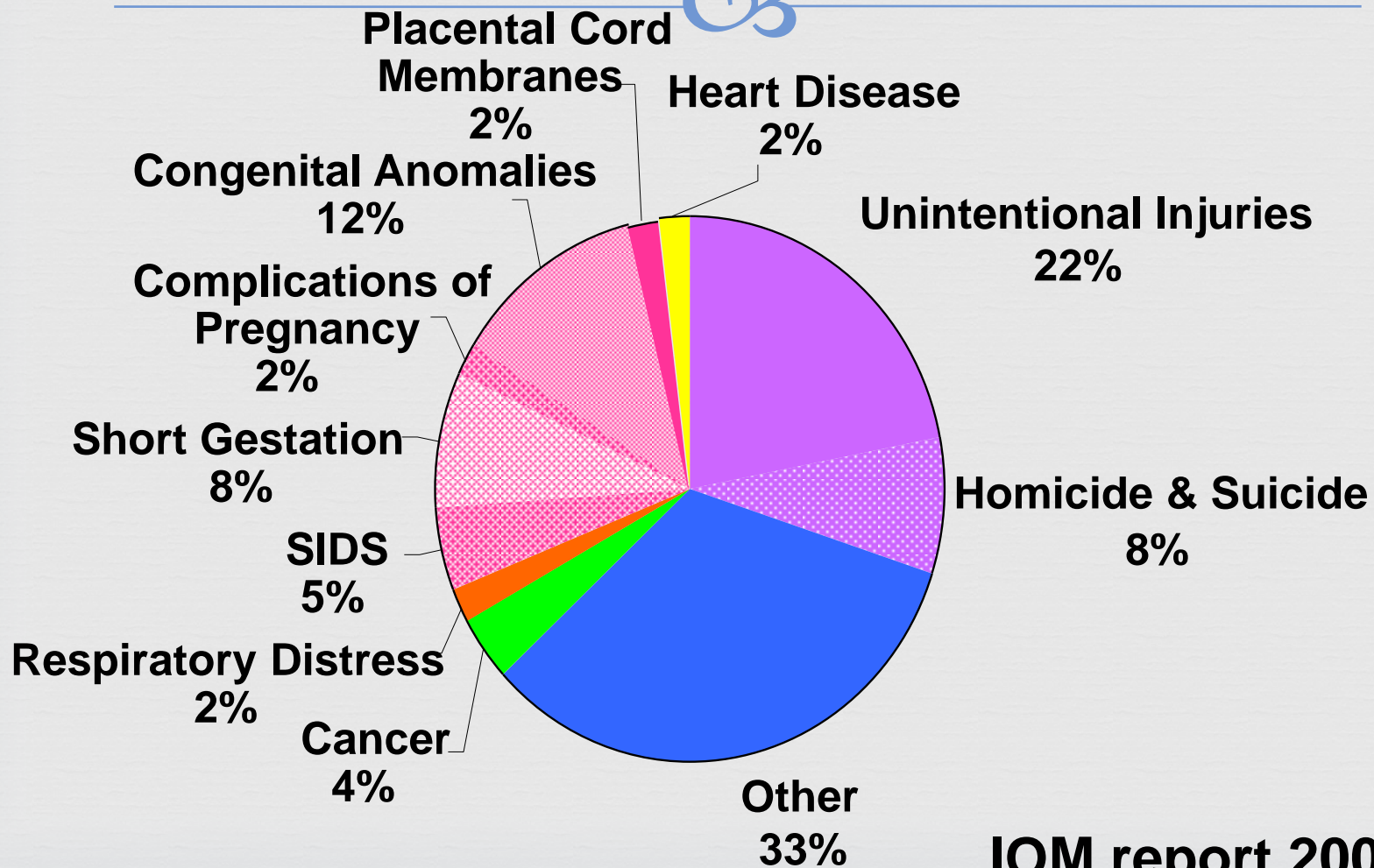


Projected deaths 0-19 years of age where PC would be of benefit – 2011 population by DHB Region



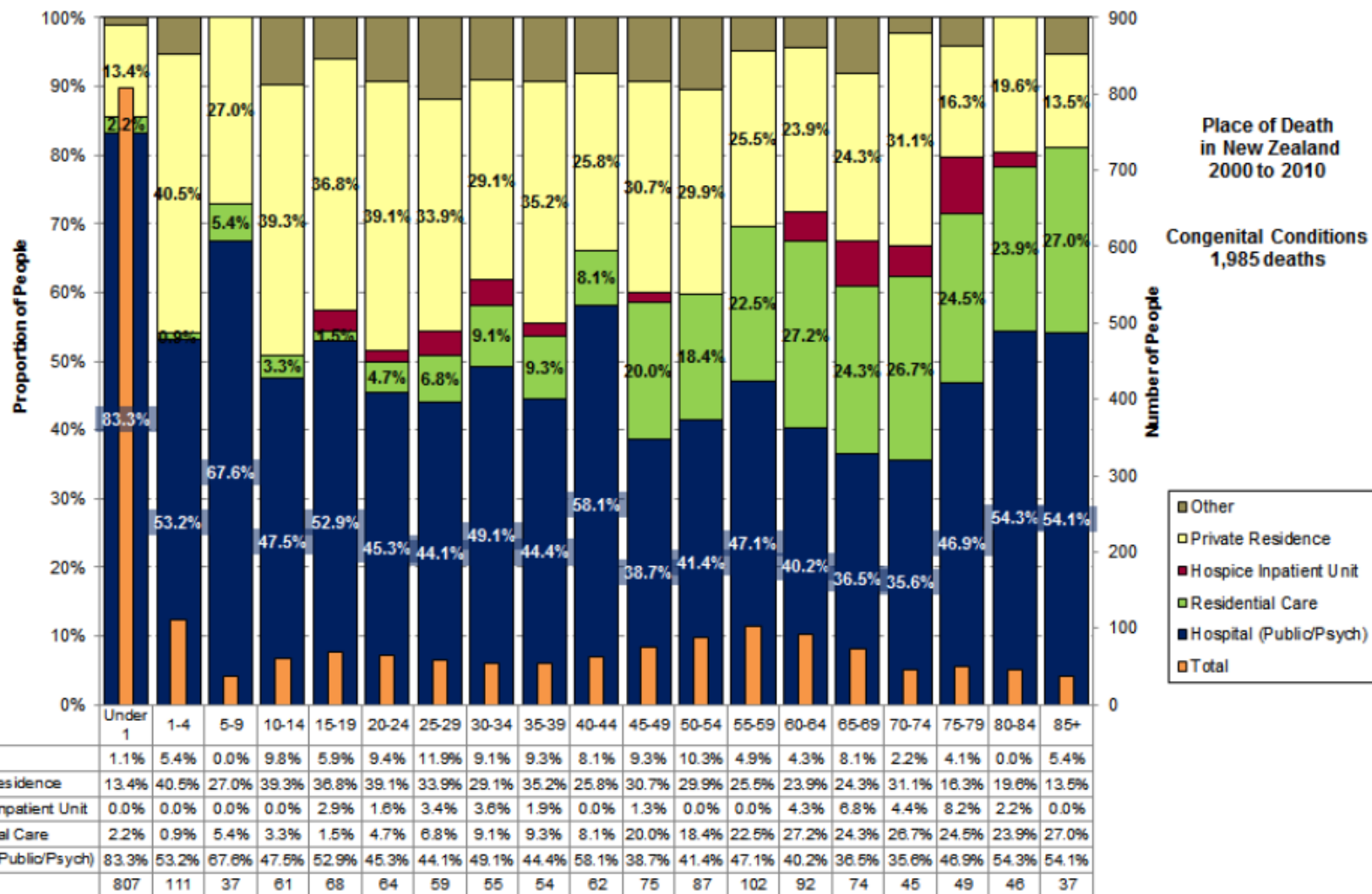
Naylor W (Senior analyst, Palliative care council of New Zealand). National health needs assessment for palliative care, phase 1 report: assessment of palliative care need. Wellington: Cancer control New Zealand; 2011. 66p

Percentage of total childhood deaths by major causes



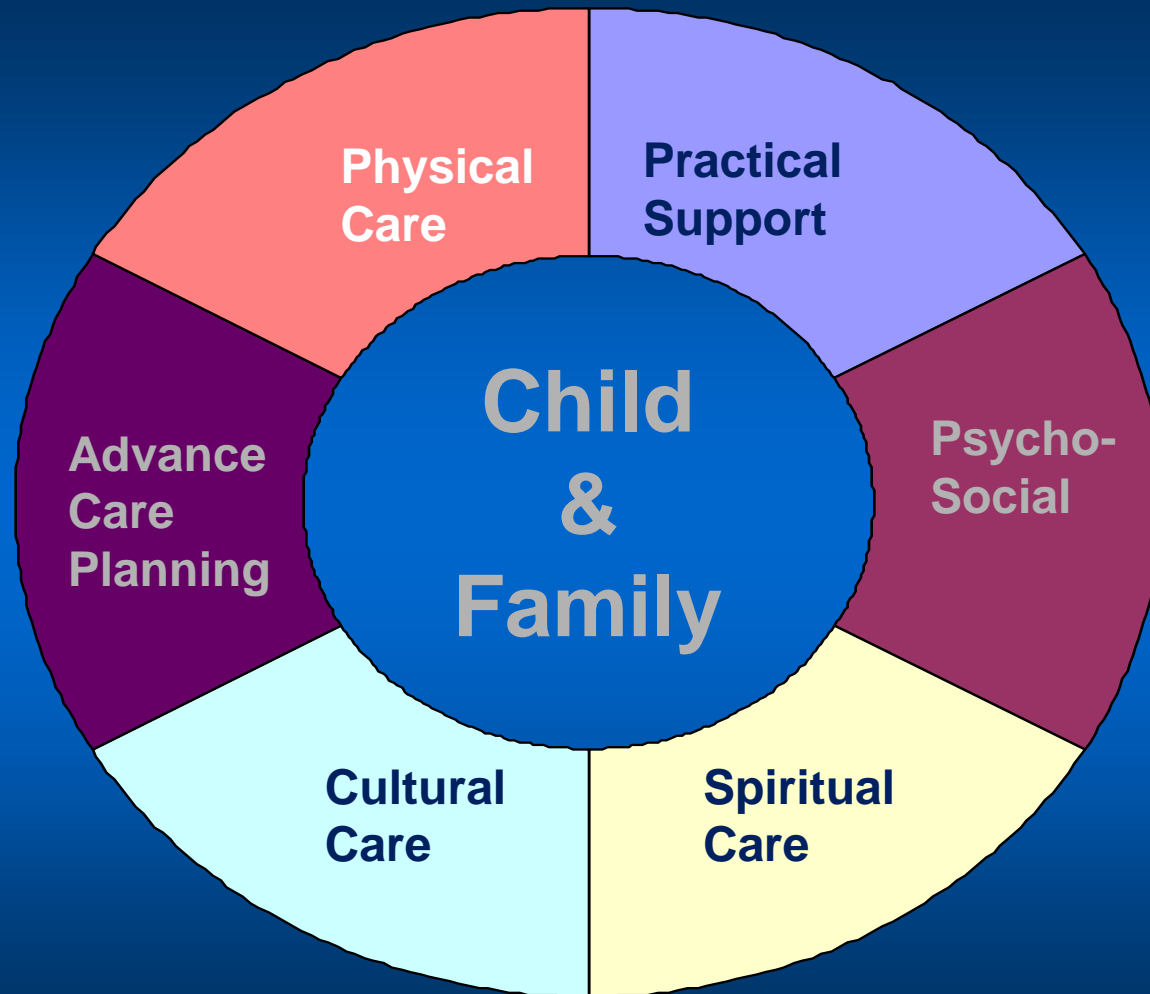
IOM report 2003

Congenital Deaths 2000-2010: Age



Source: Analysis of Ministry of Health MORT data 2000 to 2010

Elements in PPC



(Himmelstein et al, 2004, and PPC NZ)

Palliative care referral or consultation

1. Newborns at limit of viability
2. Newborns or fetuses with congenital anomalies that are incompatible with prolonged life
3. Newborns with complex and multiple birth defects or newborns with overwhelming illness not responding to medical intervention

Palliative care for critically ill neonates

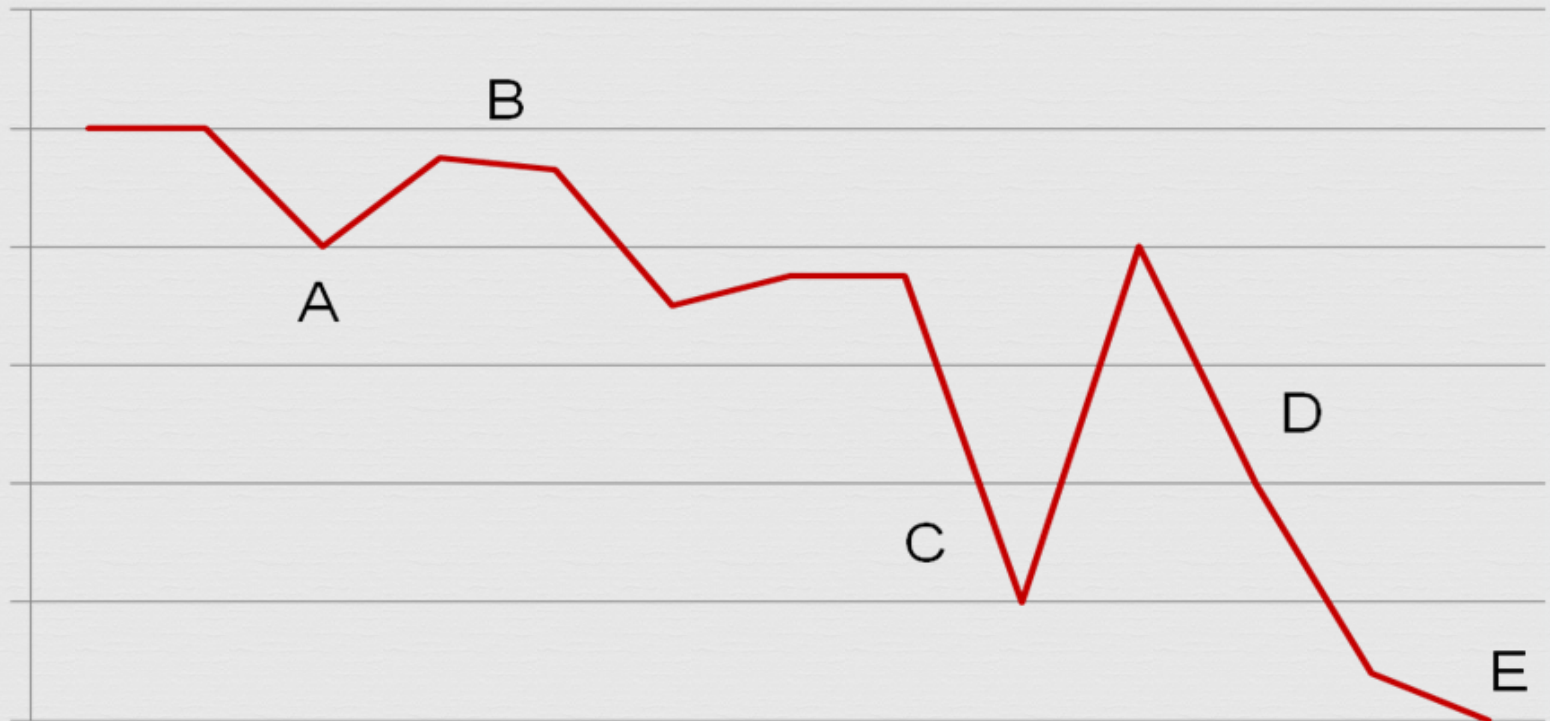
Many of the healing components of palliative care...those meeting the cognitive, emotional and spiritual needs...are geared more towards the infants' family members.

Stokowski, L. (2004). Palliative Care and Neonatal Loss. *Medscape Nurses*. Medscape, LLC.

Predictable opportunities to initiate PPC



Healthy/Functional Status Over Time



Focus or Direction of Care



“ There is always something that can be done for an infant and family, even if it is only to be present for the family, to comfort them, to hold their hands, to let them know others care...”

Orloff, SF. Et al. 2004 Psychosocial and spiritual needs of the child and family. Palliative Care for Infants, Children and Adolescents: A Practical Handbook

PPC Approach to care



- ∞ Multidimensional
 - ∞ Wide range of services in provision of care
 - ∞ Primary, secondary, tertiary, quaternary
 - ∞ Across DHB's

- ∞ Health professional/services communication & working together

- ∞ Many services involved over many years and even into adulthood

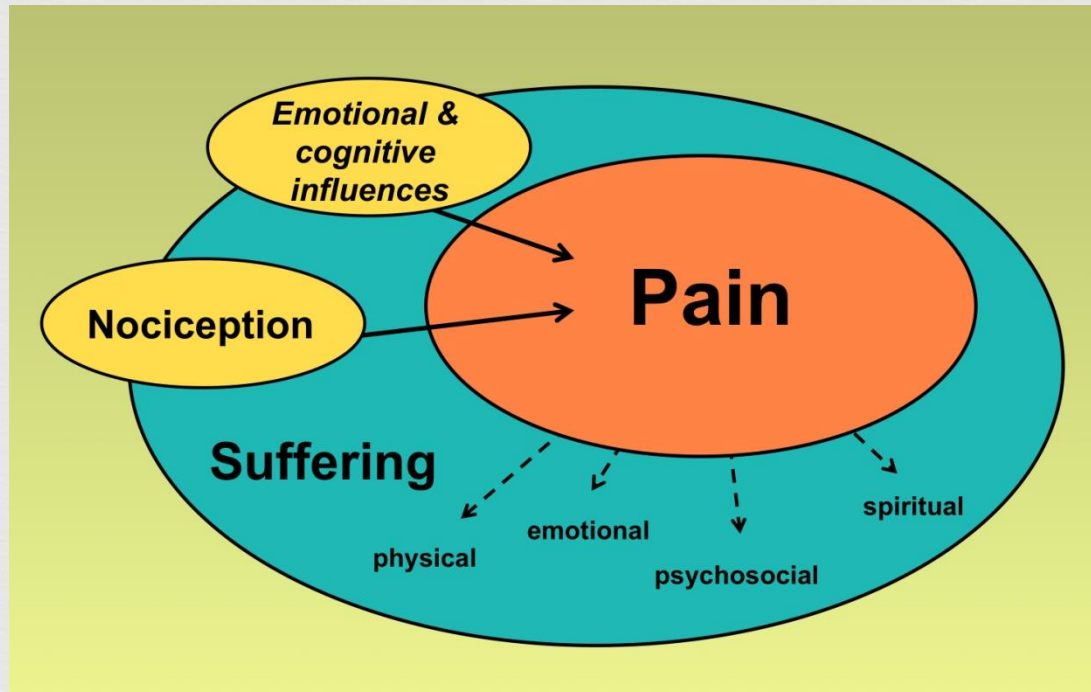
Guidance Document for Integrated Paediatric Palliative Care services in NZ; Ministry of Health; Sept 2012



- ❧ Adherence to the World Health Organization definition of Paediatric Palliative Care
- ❧ Philosophies of child and family-centred care
- ❧ Care that is provided in a preferred setting
- ❧ Care that is based on need and implemented throughout the illness course, from the point of diagnosis to bereavement
- ❧ Collaborative decision-making
- ❧ Service delivery by appropriately experienced providers
- ❧ Multidisciplinary teams
- ❧ Integrated provided networks
- ❧ Key workers
- ❧ Respite care
- ❧ 24 hour support, 365 days a year

Pain is an important component of suffering

- ☞ Pain interacts with other distress and contributes to overall suffering in patients





Paediatric Palliative Care in New Zealand - Clinical Guidelines for End-of-Life Care

Produced by the National Paediatric Palliative Care Clinical Network
Development supported by the Ministry of Health (2015)

The following guidelines have been developed by the National Paediatric Palliative Care Clinical Network with the support of the Ministry of Health and are intended to be used by secondary medical, nursing and allied health providers who care for babies, children and young people at the end of life. It is not intended that the guidelines be used by primary care providers or by providers in neonatal intensive units. **These guidelines are not suitable for use outside the Palliative Care setting.** You can read more about the **background of this project**, an **introduction to the guidelines** or the **developmental methodology**.

Filter by:

All	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	T
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A

Agitation - management in the palliative patient Updated Aug 2015

B

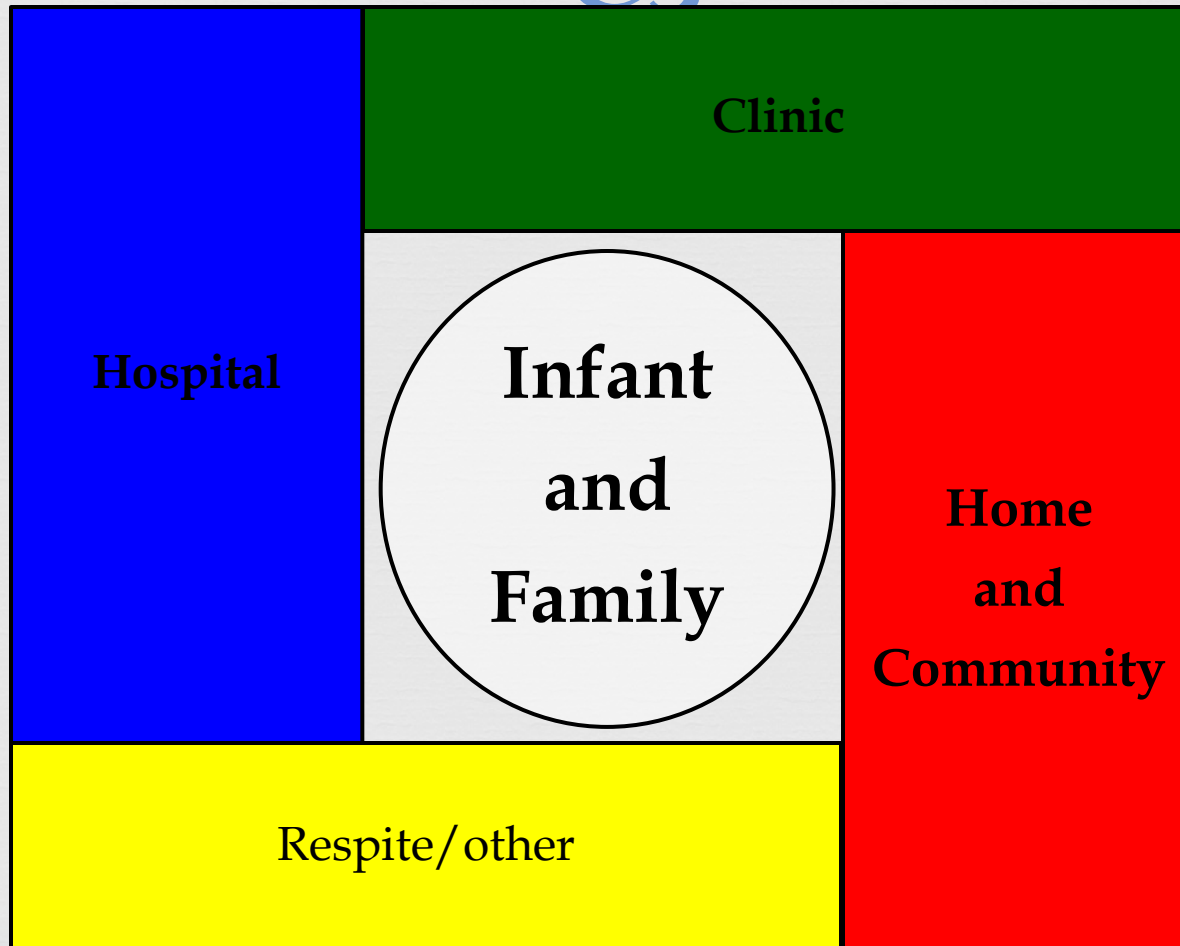
Bowel Obstruction - management in the palliative patient Updated Aug 2015

Breathlessness - management in the palliative patient Updated Aug 2015

Impact of neonatal palliative care

- **Infants with serious illnesses and their families benefit from PPC**
- **Earlier initiation of PPC improves symptom management & quality of life**
- **May lead to prolonged life**

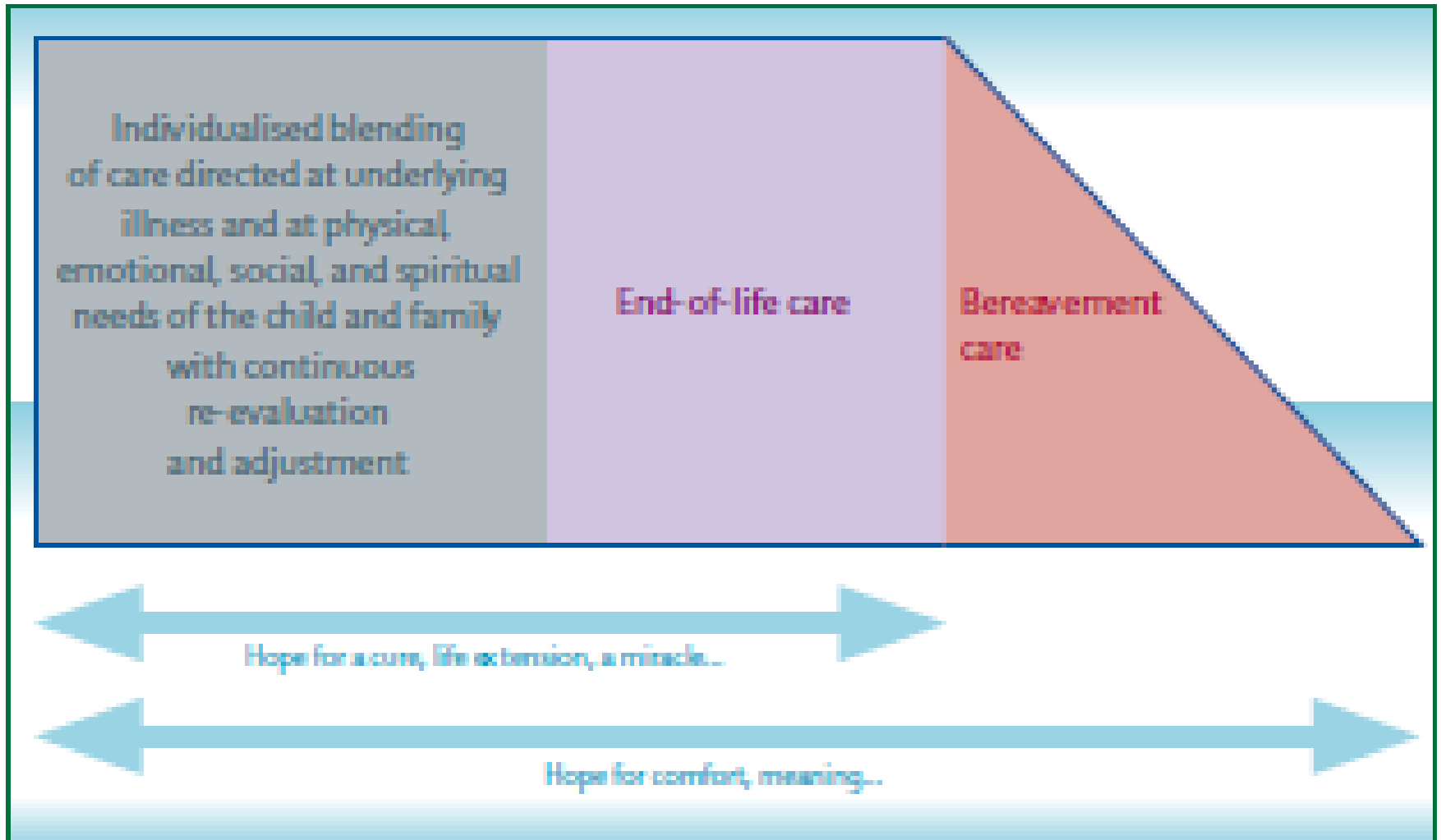
Where are PPC services offered?



Infants and their families / whanau

- ∞ Many services involved
 - ∞ May not be “one” key worker but several or one service may assume the primary role
 - ∞ Increased uncertainty of trajectory and future
 - ∞ Longer term impact on families
-
- ∞ Improvement in comfort & quality of life becomes even more paramount

Stages of Palliative Care



Promoting healing



Moving from suffering to a sense of wholeness

- ✧ Does not depend on function of organ systems or homeostasis or on cure of disease
- ✧ Fostered or hindered by health professionals
- ✧ Reframing

Reframing Hope



- ☞ Hope for a cure
- ☞ Hope for stabilization
- ☞ Hope for a slow course of deterioration
- ☞ Hope for maintenance of communication
- ☞ Hope for a short terminal phase
- ☞ Hope for no suffering
- ☞ Hope for a peaceful death

Factors Influencing Parental Readiness To Let Their Child with Cancer Die. Kars et al. Paedr Blood Cancer 2010;54:1000-1008

Hope in clinical practice



- ❧ Important for both living and dying
- ❧ Living with hope and hoping for something
- ❧ Reflective practice while continuing to care
- ❧ Affirming & communicating hope
- ❧ Contextual (emotional, cultural, spiritual, values & beliefs)

Communication and End of Life Decision Making

- ∞ “It is an art to share painful news with any patient”
- ∞ Patients often stress that “it was the sense of empathy which counted more than the immediate tragedy of the news”
- ∞ Elizabeth Kubler-Ross.

Compassion and Communication

- This conversation will change this family forever
- Can be done in different ways and times
- Done through trusted relationships and ethos of shared decision making
- Parents must never be left with feelings of abandonment or the perception that this is a task that needed to be completed/out of the way/or was a box to be ticked

The Use of Self

∞ “The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to walk through water without getting wet”

∞ Rachel Naomi Remen

Te Wa Aroha: Allow Natural Death



Advance Care Plan

Te Wa Aroha / Allow Natural Death

Te Wa Aroha / Allow Natural Death and providing palliative care does not indicate a withdrawal of care, but the provision of symptom management; psychosocial, cultural and spiritual support and comfort during the end of life period.

MUST ATTACH PATIENT LABEL HERE

SURNAME: _____ NHI: _____

FIRST NAMES: _____ DOB: _____

Please ensure you attach the correct visit patient label

T
E

<https://www.starship.org.nz/for-health-professionals/starship-clinical-guidelines/#P>



Advance Care Plan



MUST ATTACH PATIENT LABEL HERE

SURNAME: _____ NIH: _____

FIRST NAMES: _____ DOB: _____

Please ensure you attach the correct visit patient label

Te Wa Aroha / Allow Natural Death

Te Wa Aroha / Allow Natural Death and providing palliative care does not indicate a withdrawal of care, but the provision of symptom management, psychosocial, cultural and spiritual support and comfort during the end of life period.

Primary Consultant _____ Date: _____

A discussion about end of life care and allowing a natural death in relation to _____ (name of child) whose diagnosis is _____ was held on _____ (date). The following people were involved in the discussion: _____

The following goals of care were identified: _____

Management Plan _____

Psychological / Social / Cultural / Spiritual support _____

TE WA AROHA - ADVANCE CARE PLAN

CR9199



Advance Care Plan

MUST ATTACH PATIENT LABEL HERE

SURNAME: _____ NHI: _____
 FIRST NAMES: _____ DOB: _____

Please ensure you attach the correct visit patient label

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Acute Deterioration Measures

In the event of an acute deterioration, the care to be provided may include, as appropriate:

Response	Yes	No	Comments
Call to arrest team			
Nasopharyngeal suctioning			
Oxygen – passive			
Oxygen – bag and mask			
Intubation			
Cardiac compression			
Electrical cardioversion			
Arrest medications			
Antibiotics			
Other (specify)			
When at home - Call Ambulance Service			

Is a referral to the Palliative Care Team needed for symptom management and or psychological / social or spiritual support of the child and family?	<input type="checkbox"/> Yes	<input type="checkbox"/> No
If yes, has the referral been made?	<input type="checkbox"/> Yes	<input type="checkbox"/> No

This reflects the care options we have discussed and agreed on.
We understand that we can change these decisions at any time.
We agree that the Advance Care Plan be reviewed in (timeframe _____)

Senior Medical Officer or Senior Nursing or Allied Health Staff completing this form	
Print Name _____	Designation _____
Signature _____	Date _____
Contact Number _____	

This advance care plan must be reviewed by the agreed time with a new form completed and placed in the clinical record

- Fax completed [to follow - CR number] ACP form with CR0008 - Clinical Alert Notification/Cancellation form to the Clinical Record Department for scanning
- Place original ACP into child's clinical notes
- Copy of ACP sent to GP
- Copy of ACP given to family
- Copy of ACP sent to St John's Ambulance service email: PCPN@stjohn.org.nz

CR9199

The following goals of care were identified:

Management Plan

Psychological / Social / Cultural / Spiritual support

Bereavement and on-going support to families







Neonatal Palliative Care
for
New Zealand
Neonatal Units

Comfort as a Model of Care

Whakamarietia rite ki te tauira o te tiaki

1st edition November 2015

A collaborative project
Facilitated by the Neonatal Nurses College of Aotearoa, New Zealand Nurses
Organisation



A Perinatal Pathway for Babies with Palliative Care Needs

Second edition 2017



www.togetherforshortlives.org.uk



Promoting excellence in
research and its translation
into clinical practice.





PRACTICE

GUIDELINES

End of life care for infants, children and young people with life limiting conditions: summary of NICE guidance

Gemma Villanueva *senior systematic reviewer*¹, M Stephen Murphy *clinical advisor*¹, David Vickers *chair of guideline committee, consultant paediatrician and medical director*^{2,3}, Emily Harrop *deputy chair of the guideline committee, consultant in paediatric palliative care*^{4,5}, Katharina Dworzynski *guideline lead*¹

¹National Guideline Alliance, Royal College of Gynaecologists and Obstetricians, London NW1 4RQ, UK; ²Cambridgeshire Community Services NHS Trust, St Ives PE27 4LG, UK; ³East Anglia's Children's Hospitals, Milton CB24 8DF, UK; ⁴Heien & Douglas House, Oxford OX4 1RW, UK; ⁵Oxford University Hospitals, Oxford OX3 9DU, UK

Summary

- Palliative care is proactive and holistic
- Provided by many professionals and teams in a range of locations
- Decision making is a dynamic process and essential to effective palliative care

Future of Neonatal Palliative Care

∞ Privilege

∞ Potentiality

∞ Hopefulness