Reflections on Social Work Practice in Paediatric Palliative Care or…. “If You Meet the Buddha on the Way, Kill Him”

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What I’m going to talk about.

• A lasting mantra
• Values
• The broad tasks of social work
• Advocacy, Companionship and Witnessing
• 4 Conversations
• Hope
• Compassionate communication and Hope
• Te Wa Aroha and what parents choose
• Our kete
If you meet the Buddha on the way ......

- A lasting mantra
- Early lesson
- In PPC – there is no answer
Values – in PPC and in Health

• The Treaty is a living document
• Partnership
• Participation
• Protection
The Tasks of Social Work in PPC

Broad Ethical Framework

- Ethical commitment to client needs and self determination
- Advocating social justice
- Honouring each person’s dignity and worth
- Understanding the importance of human relationships
- Practicing with integrity and competence
- Ethics 101...

The Tasks of Social Work

• Social workers should act in relation to the people using their services with compassion, empathy and care*
  • Compassion – to treat others with dignity, equity and respect – the basis of Partnership
  • Empathy – the ability to understand and share the feelings of another – the basis of Participation
  • Care – the provision of what is necessary for the health, welfare, maintenance and protection of someone or something – the basis of Protection
• IFSW/IASSW Ethics in Social Work, Statement of Principles
The Tasks of Social Work....

Broadly Speaking

- Assessment skills – the role of the naïve listener
- Pain control and symptom management
- Cultural understanding*
- Crisis management
- Counselling and support – child and family
- Information
- Resourcing – “concrete services”
- Quality of life focus
- **Advocacy**, negotiation and empowerment
- **Companionship and Witnessing**

*Last Words: Approaches to Death in New Zealand’s Cultures and Faiths, Compiled by Margot Schwass. Bridget Williams Books Ltd, 2005
Advocacy – Finding our Voices

• Advocacy is the process of supporting and enabling people to express viewpoints and concerns, provide information and services, to defend and promote rights and responsibilities.

• Social work advocacy is the exclusive and mutual representation of clients or a cause in a forum attempting to systematically influence decision making in an unjust or unresponsive system.

• **Change happens by pushing from within as well as from outside of organisations**

Advocacy – “Ring the Bells that Still Can Ring” - Cohen

- Conflict over resources – “Can you guarantee this child will live 6 months or more”
- Social Justice – Poverty/Social Housing/the media/in PPC
- Standard of Advocacy - A Letter and a Right in a Democracy
- “Action for social change that is necessary to achieve social justice”
- Conflict within an organisation - “Social workers should not allow an employing organisation’s policies procedures, regulations or administrative orders to interfere with their ethical practice of social work” – agents for change or for control?

NZASW – Code of Ethics
That's how the light gets in...

- Quiet advocacy behind the scenes
- Children’s Hospice – that vexed question – would you have used it?
- Future advocacy – national respite centre, extramural hospice
Companionship in PPC

- I will take this ring..... Though I do not know the way

- The right companion for each part of the journey – determined by the child’s need and the whanau choice
Companionship

‘When we honestly ask ourselves which persons in our lives mean the most to us, we often find it is the person who instead of giving advice, solutions or cures, [has] chosen...to share our pain and touch our wounds with a gentle and tender hand. The friend who can be silent with us in a moment of despair or confusion, who can be silent with us in our hour of grief and bereavement, who can tolerate not knowing, not curing, not healing, and face with us the reality of our powerlessness, this is the friend who cares. (Palliative Care for Infants, Children and Adolescents, Ch 6).
Witnessing

- Knowledge from observation or experience.

- “Wisdom is the ability to think and act using knowledge, experience, understanding, common sense and insight” – Wikipedia

- “By three methods we may learn wisdom:
  - First, by reflection, which is noblest;
  - Second, by imitation, which is easiest
  - Third, by experience, which is bitterest” - Confucius
But the Greatest Teachers of all...

- Our colleagues and the teams we are in

- The Children and Families/Whānau we are privileged to work with
Four Conversations – and the Three Ps

- Will my tumour make me dead?
- He is seven, will always be seven and he lives in my heart
- Tell them I made it to University
- You know I could kill you Jess
Will my Tumour Make Me Dead - Partnership

• A conversation and a promise that began a partnership

• Small children aren’t meant to ask questions like that
Reflection

• The beginning of my lifelong interest in how devastating news is given to parents

• Talking to children/young people about dying and death

• The concept of agape love or, in the words of Janis Joplin, “take another little piece of my heart now”
Josh and Participation

• You will think I’m strange but I need to talk about this

• We’re going to treat you with love, we’re going to take you home home and were going to see what love can do
Reflection

• Quality of life – truly living until he said goodbye

• The beginning of an interest in advance care planning

• Words I still use – 20 years later – “he lives in my heart”

• That parents do find joy again – but lives are changed forever
Special Teenagers – Protection

- Nancy – parental permission
- Patient A – PPC (me) was sacked
- No she does not need to talk about it
- Patient B – an outstanding example
- Texting – passing them on
Reflection

• Walking in two worlds – “tell them I got to university”

• The importance of dignity – from others and to others – the quality of nursing care

• They live on, we walk out the door

• The role of companioning and – connection/awhi/just being there
Sometimes it Just Doesn’t go to Plan

• “You know I could kill you Jess”

• Finding words when I was speechless

• Addressing overwhelming pain – they came to my home, they showed me they cared, I’m not angry anymore
Reflection

- That grief is overwhelming – “I live with a hole in my heart....”

- That courage is something we draw upon in all aspects of our work

- “Courage is what it takes to stand up and speak; courage is also what it takes to sit down and listen” Winston Churchill
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 competed/out of the way/or was a box to be ticked

- In the words of Confucius – “When you are labouring for others let it be with the same zeal as if it were for your self”
Hope – a Vital Ingredient

• A Wise Theologian – “as the body falls away, the mind turns towards the spirit”

• A wise Australian -“in the end we don’t live our lives in despair, we live our lives finally fuelled by hope. I think Nietzsche said ‘hope is the cruelest of torments because it prolongs life’ but it is also the engine of us. Without it we die. It is something that is utterly fundamental to us. If you wish to go into the darkness and not have hope, then I think people sense there is something fundamentally untrue about the art. And to me love is the highest expression of hope” – Richard Flanagan
Hope for the Family

- Transitioning Hope:
- Hope for a cure
- Hope for stabilisation
- 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, Pediatr Blood Cancer, 2010; 54

- **Hope that we will be able to look back and know that we did everything we could - and that we had support to do it**

- **And Hope that we will find joy again**
Hope for the Child

• Ann Goldman – to have love, choices, to be treated with honesty, to have peace, to still be me, to have dignity, to be able to express emotion, to be able to use the remaining time, to have communication, to still have hopes and goals, to have physical care.

• A sense that I will be remembered, that my life had meaning - A wise mum and on-going connection
Confucius and Advanced Care Planning in PPC

• “Wisdom, Compassion and Courage are the three universally recognized moral qualities of man”

• Te Wa Aroha – Allow Natural Death

• Intent of Plan: “to prevent suffering and promote comfort, quality of life and dignity”

– Parental Hopeful Patterns of Thinking, Emotions and Paediatric Palliative Care Decision Making, Chris Feudtner, Arch Pediatr Adolesc Med/Vol 164. No 9, Sep, 2010
Te Wa Aroha – What Do Parents Choose?

• 73 plans reviewed
• 23% chose Review – admission to Paediatric Intensive Care Unit and Intubation.
• 10% chose Allow Natural Death – no intervention apart from the consideration of antibiotics
• 67% chose Comfort Care – antibiotics, passive oxygen, short period of bag and mask and possible cardiac compression (to allow the possibility for family to arrive (but to be guided by health staff), no further cardiac intervention.
Projects along the Way

• Animals in Hospitals
• The Freezer Project
• Adopt-a-Family
• Guardian Angels - the work of two wonderful women
In Our Kete/Basket

- The teams we are part of – MD skills and expertise
- Knowledge of self
- Reflection upon our own dying/death
- A true understanding of the three Ps; Partnership, Participation and Protection
- On-going learning, training and support
- Supervision – the ability to reflect
- Self-care skills
Soul Sore/Soul Soar

• Courage
• Listening skills—God gave us two ears and one mouth so that we can listen twice as much as we speak—American Indian proverb
• Balance
• Joy and Laughter
• Own our own tears
• Our own Turangawaewae
If You Meet the Buddha Along the Way, Kill Him *

• “I hear, I know,
• I see, I remember,
• I do, I understand” – that man Confucius again

• Just as we are, each child and each family is unique and must find their own way

* Sheldon B Kopp
And by the Way....

- A mother’s recollection
- A moment along the way – the greatest gift of all
Whakatauki

Kia hora te marino
Kia whakapapa pounamu te moana
Kia tere te karohirohi i mua i tou huarahi ara nei a ake tonu atu.

May the calm be widespread
May the sea glisten like greenstone
And may the shimmer of sunlight ever cross your pathway in life – now and always.