

Difficult conversations and Advanced care planning

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Overview . . .

Referral to hospice and when to refer

What is palliative care? (what do we do?)

Quality of life

Having difficult conversations

What is ACP and why?

Points to think about

Palliative care happens everywhere

So **EVERYONE**
needs knowledge
and skills and
understanding of
key principles of
palliative care to
support patients
and their families



Palliative care definition

Palliative care is the provision of caring and dignified support and services for people of all ages facing a life-limiting condition. It is provided wherever the person is, whether that is in the home, hospital, community clinic or hospice.

WHEN DOES TRANSITION TO PALLIATIVE APPROACH HAPPEN

**Hospice
is not just
a building;
it is a
philosophy
of care**

Hospice Awareness Week
13-19 May 2019

www.hospice.org.nz



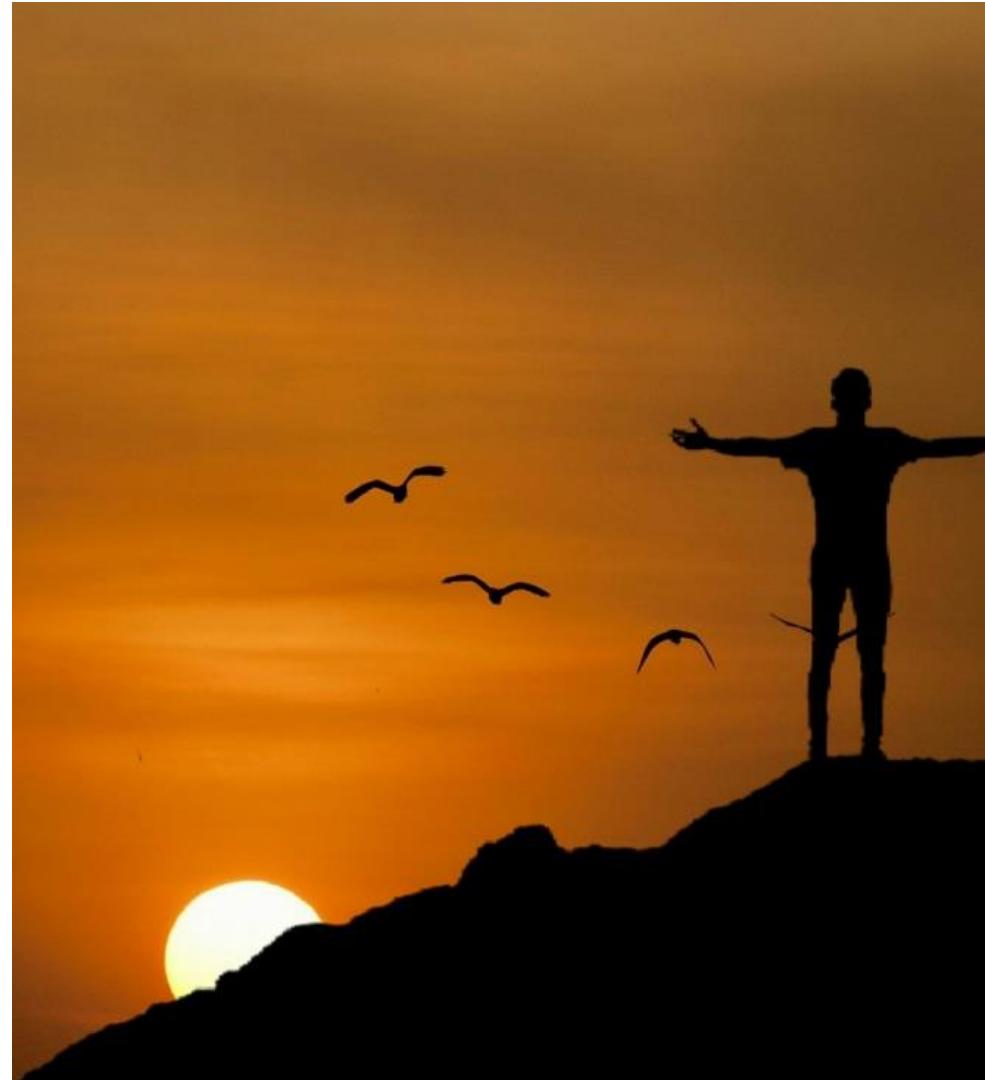
Living Every Moment
hospice
New Zealand

Referral Guidelines for MND to specialist palliative care . . .

Motor Neurone Disease

- Marked rapid decline in physical status
- First episode of aspirational pneumonia
- Increased cognitive difficulties
- Weight Loss
- Significant complex symptoms and medical complications
- Low vital capacity (below 70% predicted spirometry), or initiation of NIV
- Mobility problems and falls
- Communication difficulties

EVEN IF I
AM DYING,
UNTIL I
ACTUALLY
DIE,
I AM STILL
LIVING







My Advance Care Plan & Guide

*Plan the healthcare you want in the future
and for the end of your life*

Name: _____

Date: _____

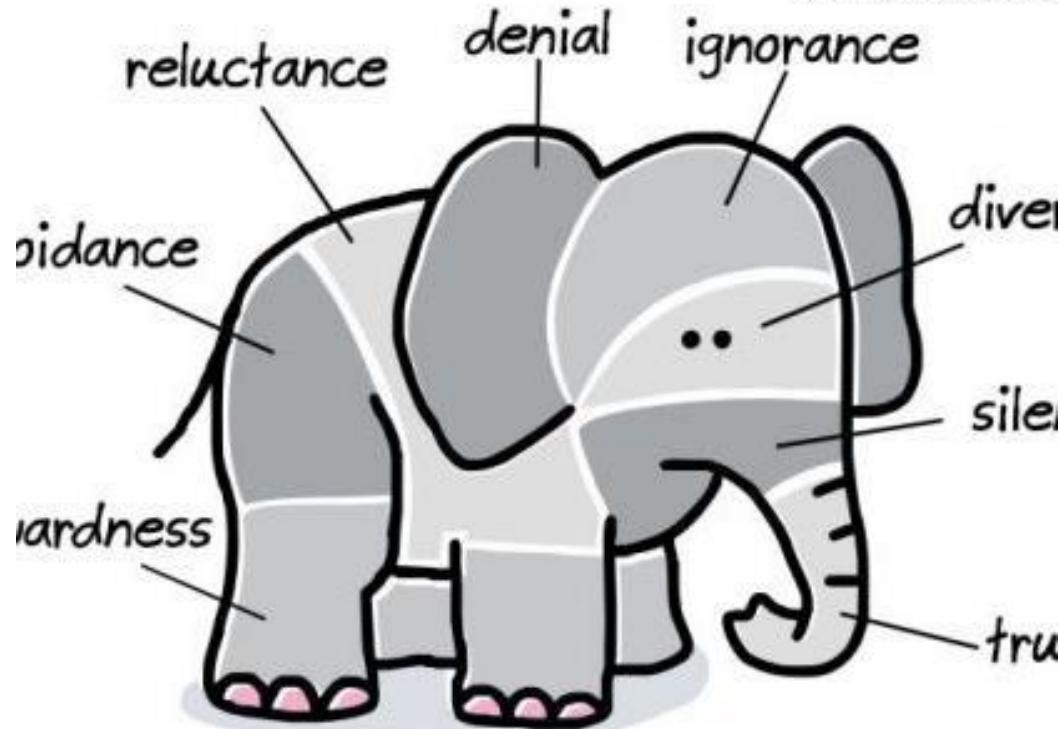
our voice
tō tātou reo



There are so many factors that make it difficult to talk about ACP or even start the conversation

PARTS OF THE ELEPHANT IN THE ROOM

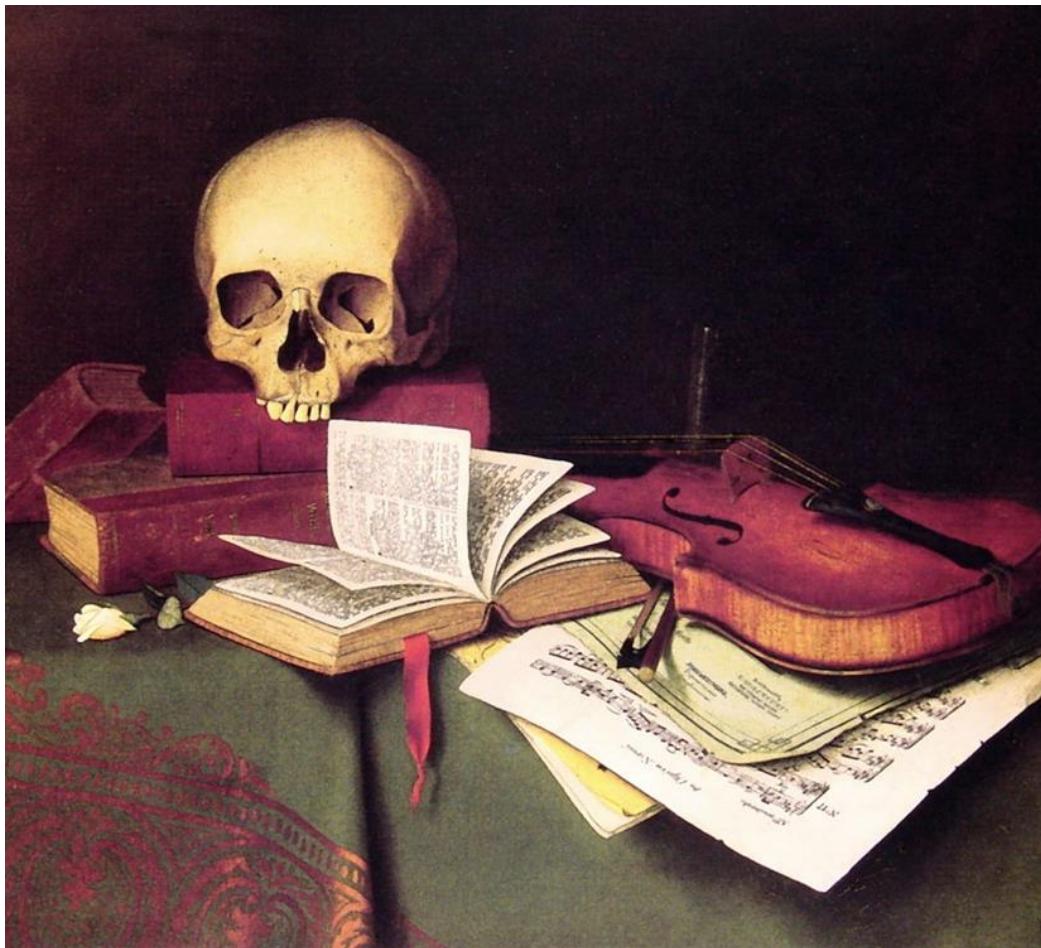
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When having difficult conversations?

- Are you the right person?
- Is this the right time?
- What cues have you had from the person themselves?
- Do you have the right skills/relationship with the patient to have the conversation
- Sometimes silence is a good thing
- Who should start the conversation
- It is okay if a person does not want to talk but we need to make sure there is the opportunity to talk



FACING OUR OWN MORTALITY



NOT JUST LISTENING BUT ACTUALLY
HEARING

CAN I
HANDLE
WHAT
MIGHT
BE SAID?



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DO I HAVE
THE RIGHT
SKILLS?



SOMETIMES I FEEL
INADEQUATE.

Why are ACP's important?



- Keeping the person at the centre
- Ensures clinical care is in keeping with the patients preferences
- Encourages deeper conversations at an important time
- Empowers and enables patients and families
- Facilitates shared decision making
- Encourages better provision of services related to patients needs and pre planning care
- Can prevent unnecessary hospital admissions and invasive procedures

For the love of plans . . .

- <https://www.youtube.com/watch?v=RlauUxwFqkI>

Patient choice is powerful



© Grafton Marshall Smith/CORBIS



IT IS ALWAYS WISE
TO LOOK AHEAD,
BUT DIFFICULT TO
LOOK FURTHER
THAN YOU CAN
SEE —

WINSTON CHURCHILL



Five difficult discussions . . .



PEG



NIV



WITHHOLDING/
WITHDRAWING
TREATMENT



WHAT TO DO IF
ANOTHER POTENTIAL
HEALTH CRISIS ARISES



WHERE DO YOU WANT
TO DIE – IS THERE A
VILLAGE TO SUPPORT IT

PEG decisions/discussions

- Should it be inserted?
- When?
- Should feeding continue?
- When should it stop, if ever?

A close-up photograph of a person's face wearing a Non-Invasive Ventilation (NIV) mask. The mask is a clear plastic device with a blue headband and a tube leading down. The person is wearing a dark green shirt. The background is a plain, light-colored wall.

NIV

- Should it be started?
- When?
- What would happen if it isn't tolerated?
- When should it stop, if ever?

If there is an infection – IVAB's?

MND patients are one of the groups who are pre disposed to chest infections

Often aspiration pneumonia

If pneumonia is present should we treat?

Is there a ceiling of treatment?





Emergency



WHAT TO DO IF ANOTHER HEALTH CRISIS ARISES

Place of death

- Where do they want to die?
- Can their choice be supported?
- Who is there to look after the carer?
- What is the back up plan



WALKING THE FINE LINE - A STORY FROM ATUL GAWANDE





To summarise . .

- Medical advances (as discussed in last slides) – but do we choose them
- Autonomy (you can refuse treatment but you cannot demand treatment)
- Health professionals are not obliged to offer treatment that is not clinically indicated eg CPR
- Treatment can be stopped if it becomes futile or burdensome or not in keeping with a patients goals of care

ACP's



- Often a chance to start the conversation
- A listening and sharing of views
- Development of a set of future care principles
- What we want changes over course of our illness
- Need to be shared with everyone
- Helps us know what are 'Goals of care'
- Helps to care for carers

How to start having those conversations

- “How do you feel things have been going recently ?”
- “If you become ill, what medical care would you like?”
- “You haven’t been so well over the last few weeks, is this something that you are concerned about ?”
- “Are there any fears or worries about the future you would like to talk about ?”
- “What would bring you the most comfort when your life is drawing to a close ?”
- “Have you thought about how you would like your last days to look? ”



**DECISIONS
CAN BE
DIFFICULT AND
NEED TO BE
REVISITED**

Sometimes patients just don't want to engage

- Don't just respond with "it's their right to know" and tell them anyway
- Some people want to know everything they can about their health, results, prognosis, what to expect. Others don't want to know very much at all or only want their family to know
- Both scenarios are fine and therefore early on we need to establish just how much the person wants to know
- Explore reason/concerns of the person, their family and whanau and how they communicate as a family
- A trusting therapeutic relationship will enable this conversation to happen
- It's about partnership





WHAT
WOULD YOU
WANT TO
HAPPEN TO
YOU?