Conference for General Practice 2013
Generalism: The heart of health care

ADVANCE CARE PLANNING WORKSHOP
Katrina Gibson, Medical Officer, Mary Potter Hospice
FRIDAY 12th JULY 2013
What we are going to cover

What is advance care planning?
Why is it important?
What does it involve?
What is happening in NZ?
Realities in Primary Care
   - Local & national perspectives

The Journey to where?
From the Emotional Cancer Journey,
Michele Angelo Petrone.
http://www.mapfoundation.org/ecj.html
WHAT IS ADVANCE CARE PLANNING?
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What is Advance Care Planning?

ACP is a process of discussion and shared planning for future health care. It involves patient, whanau and health care professionals.

ACP gives patients the opportunity to develop and express their preferences for end of life care based on:

- their personal views and values
- a better understanding of their current and likely future health
- the treatment and care options available.
What is Advance Care Planning?
Living for Today

Planning for Tomorrow
WHY IS ACP IMPORTANT?
Why is ACP important?

- Ongoing advances in medicines & medical technology.
- People are living longer, often with chronic diseases.
- Increasing recognition of the importance of patients having a voice in their care.
WHY IS IT IMPORTANT IN PRIMARY CARE?
I'm sorry Mr. Murphy. You're going to die.

Forever.
Why are ACP conversations so difficult?
Barriers to ACP conversations

- Cure culture
- Specialisation
- Paternalism
- Not comfortable talking about it
- I don’t know how
- I don’t have the time
- Complexity of prognostication
“The diagnosis of 'dying' is often avoided by health care professionals as much as by the patient, and this may mean that treatment, especially if the patient arrives in hospital severely ill, may be inappropriate. Medical interventions motivated by a ‘we can fix it’ mentality, may now be futile and simply prolong the discomfort rather than relieve it.”

(Professor Robin Taylor – University of Otago)
Henrik - Heather's bereaved husband
Why bother?

People only die once; they have no experience to draw upon.

They need doctors and nurses who are willing to have the hard discussions and say what they have seen, who will help people prepare for what is to come.

Gawande, A. (2010): Letting go, Annuls of Medicine, The New Yorker
Is there any evidence that Advance Care Planning helps?

• It’s not just about the paperwork!

• Growing body of evidence that it’s about the conversations & the general process
The impact of advance care planning on end of life care in elderly patients: randomised controlled trial

Karen M Detering, respiratory physician and clinical leader,1 Andrew D Hancock, project officer,1 Michael C Reade, physician,2 William Silvester, intensive care physician and director1

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Cite this as: BMJ 2010;340:c1345
doi:10.1136/bmj.c1345

ABSTRACT
Objective To investigate the impact of advance care planning on end of life care in elderly patients.
Design Prospective randomised controlled trial.
Setting Single centre study in a university hospital in Melbourne, Australia.
Participants 309 legally competent medical inpatients aged 80 or more and followed for six months or until death.

decisions,1-3 resulting in patients being cared for in a way they would not have chosen.2 This has continued to the present day.4 Apart from progress in palliative care, the main focus to deal with these needs has been the development of advance care planning. Advance care planning is a process “whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care should he or she become incapable.
Is there any evidence that Advance Care Planning helps?

• More likely to lead to awareness and respect of patient preferences re end of life care wishes

• Family members more likely to be satisfied with the quality of the patient’s death & the belief the patient would have been satisfied with this

• Helps decrease stress, anxiety and depression in surviving relatives
Is there any evidence that Advance Care Planning helps?

• Concern that ACP may limit access to medical treatment
  • No evidence to suggest this at present

• BUT – Health care professionals need to be aware of documentation & use it.
What does ACP involve?

Conversations
Important conversations ...
Seek insight...

**Process** is most important

An assumption that this is a simple and easy process would be wrong – it requires considerable skill and sensitivity due to the deep **significance of the subject**
What do we need to do?

- ID
- Intro
- Initiate
- Facilitate
- Document
- Participate
- Review

Patient can NO longer direct own care
First
If something unexpected occurred, are there circumstances where you would you like treatment to change to comfort? EPoA

Next
Diagnosis, acute episodes Next episode might not have such a good outcome – if things did go bad what would you want, how would you like us to care for you? Traditional ACP

Last
12 months Detailed Planning and documentation of treatment & care preferences
ACP Conversations may include:

- Understanding of illness - prognosis/outcome
- Types of care and treatments that may be beneficial
- Person’s preferences for future care and treatments
- Person’s concerns, fears, wishes, goals, values and beliefs
ACP Conversations may include:

- Person’s preferred place of care
- Family members to be involved in decisions – appointing an EPA
- Person’s views and understanding about interventions (i.e. cardiopulmonary resuscitation)
- Person’s needs for religious, spiritual or other personal support.
Legal Aspects
Definitions

Advance Care Plan
• An articulation of wishes, preferences, values and goals relevant to all current and future care
• May include an Advanced Directive

Advance Directive
• Instructions that consent to, or refuse, a specified medical treatment or procedure in the future
Advance Care Plan & Advance Directives

• May be in any form – written or oral
• Are ideally documented
• Can be revoked at any time whilst the individual is competent
• Should be used to inform decision making along with other measures including discussions with the EPA/family/whanau
Advance Directive

• Defined in Code of Health & Disability Services Consumers Rights
• Only applies when patient is no longer competent
Advance Directive

• Has legal authority if deemed ‘valid’

• Requirements for validity:
  – Individual must be competent
  – Free of undue influence
  – Intended to apply in the circumstances arisen & individual sufficiently informed when making decision
  – Existence & validity of AD clearly established
Advance Directive
- REFUSAL

• An EPA can not refuse any standard medical treatment or procedure intended to save life or prevent serious damage to health.

• An advance directive is therefore the best way for an individual to express their wish to refuse a particular treatment in future (particular if it is considered standard/potentially life-saving)
Advance Directive
– CONSENT/POSITIVE PREFERENCE

• A patient’s desire, wish, request or expectation to receive a treatment does not establish a duty on the health care provider to provide it

• If a treatment or procedure is not indicated and/or would offer no benefit the individual’s wishes do not take priority over the clinical decision

• The individual’s wishes can be taken into account along with clinical judgement regarding the course of action that is in the individual’s best interests
When patient is not competent

Advance Directive

Is there someone else who has authority?

EPoA (personal welfare) / Court appointed welfare guardian

If not, then

– Clinician makes the decision based on ascertainable views of patient or

– Clinician makes the decision in the patient’s best interests taking into consideration views of other suitable people
What’s happening in New Zealand?
National ACP Cooperative

• Research
• Tools
• Consumer Engagement
• Education

“All people in NZ will have access to comprehensive, structured and effective advance care planning”

www.acp.hiirc.org.nz
MoH guidelines for health workforce

- Standardised info about ACP principles and legislation
- Aims to promote consistency
- Will assist in the development of local policies, guidelines & training in ACP

We are busy building a website which we hope will meet your needs.

We already have some great resources to help you think about, talk about and plan for the care and treatment you would like at the end of life; you just need to click on the links below.

We would really appreciate it if you would let us know what other information you would like to find on this website in the future (click here to send us an email).

- Advance care planning guide
- Advance care planning Leaflet
- Making the most of your final years leaflet
- My advance care plan form
- **A Good Death**
  - a short film about Martin’s journey and the role advance care planning played.
  - “film produced by PRMI ms”

http://www.advancecareplanning.org.nz
Consumer resources

Making the most of your final years
Practical and spiritual things to think about and plan for end of life

Advance care planning
Preparing for end of life

Advance care planning guide
Planning for the medical treatment and care you want in the future

MY ADVANCE CARE PLAN
(Page 1 of 4)

If you have had a chance to think about the care you want towards the end of your life, you may want to write down your thoughts. Use this plan to write down what you want health professionals, friends and family/whanau to know if you could no longer tell them yourself.

There is a section on medical treatments which is important to discuss with your doctor if possible before you complete it.

This plan is for you and about you. Complete as much as you want. You can show it to anyone involved in your healthcare. You can add to it as often as you like and change your decisions at any time. Please take it to your doctors or nurses to discuss it and then you can both have copies. It can be forwarded through your doctor to others who may need it, with your consent.
Education

Films

E-Learning modules

Support & Resources

Communication skills training

Conversations about end of life are challenging and many of us struggle with them.

Training: Advance care planning

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<thead>
<tr>
<th>Module</th>
<th>Level</th>
<th>Short description of course content</th>
<th>Associated healthcare workforce</th>
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<tbody>
<tr>
<td>Module 12</td>
<td>Level 4</td>
<td>To be developed – NZ Level 4 training</td>
<td>1-2 Super trainers nationally</td>
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<tr>
<td>Module 11</td>
<td>Level 3</td>
<td>17 days training over 3-6 months – NZ Level 3 training</td>
<td>14-18 Facilitators nationally</td>
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<tr>
<td>Module 10</td>
<td>Level 2</td>
<td>ACP Case studies (learning) &amp; completion of 10 ACP conversations (clinical practice)</td>
<td>Healthcare professionals who want to improve their communication skills and ACP documentation</td>
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<td>Module 9</td>
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<td>Module 8</td>
<td>Level 2</td>
<td>Applying Communication skills to inpatient and outpatient ACP conversations, negotiating important care and treatment preferences</td>
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<td>Module 7</td>
<td>Level 2</td>
<td>Communication skills, currently practiced and for level 2</td>
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<td>Module 6</td>
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<td>Translating a patient’s ACP into healthcare choices and treatment options</td>
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<td>Module 5</td>
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<td>Legal Framework, ACP, advance directives &amp; EHPs</td>
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<td>Module 4</td>
<td>Level 2</td>
<td>Identifying patients who would benefit from ACP &amp; initiating a conversation</td>
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<td>Module 3</td>
<td>Level 2</td>
<td>Identifying the barriers (personal, healthcare system/setting/limbic)</td>
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<td>Module 2</td>
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<td>Overcoming the barriers</td>
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<td>Module 1</td>
<td>Level 2</td>
<td>Complicating your own ACP &amp; reflection on how to feel</td>
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<tr>
<td>Module 0</td>
<td>Level 2</td>
<td>What is ACP, the benefits of ACP, why is it important &amp; where to get more info</td>
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<td>Module 10</td>
<td>Level 1</td>
<td>Setting yourself up for success – organisational ACP policy, procedure &amp; process</td>
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<td>Module 9</td>
<td>Level 1</td>
<td>ACP changing outcomes – Legal Framework ACP, advance directives &amp; EPHP</td>
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<td>Module 8</td>
<td>Level 1</td>
<td>Talking about ACP – (1) Identifying the barriers (personal, healthcare system/setting/limbic) (2) Overcoming the barriers (3) Identifying patients who would benefit from ACP &amp; initiating a conversation</td>
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A Local Pilot

Kapiti
Kapiti Locality ACP pilot

Objectives:

1. Embed ACP processes within Primary Care
2. Integrate IT to allow sharing of plans between health professionals
3. Ensure Health professionals are confident and competent to have ACP conversations
Kapiti Locality ACP Pilot

- Six GP practices involved
- 2 Aged Residential Care facilities
- Providing info packs – engaging patients in conversations
- Completing ACP forms
- Sharing of Information
Kapiti Locality ACP Pilot

Strengths:

• Increased ACP activity – lots of interest amongst patients/at rest homes
• CPD training/ Level 2 practitioner training
• Considered alignment with Care Plus
• Building bridges between providers (Emergency Department, InterRAI, Needs Assessment Teams, Ambulance)
Kapiti Locality ACP Pilot

Difficulties

• Vulnerable populations unable to afford extra consult time
• Electronic means of sharing ACP information still in infancy – read coding essential
• Ensuring culturally appropriate approaches
• Practice staff struggling to attend 2.5 days Level 2 training
DISCUSSION

Whose role is it?

Health literacy

Linking in with current strategies

Funding?

IT

Documentation

Cultural & language barriers

How can wishes be shared across all settings efficiently & safely?
What do we need to do?

Help people understand what the future might hold

So they can be better prepared

and we can be better informed to make decisions in the patient’s best interests

Painting the future. Andrew Judd. 2009
Thank You

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Enquiries about website – acpcoop@adhb.govt.nz / training courses etc – acpadmin@adhb.govt.nz