1er colloque d'experts internationaux en soins palliatifs

1st international palliative care experts symposium

Advance Care Planning – who, what, why?

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Scoil an Altranais, an Cnáimhseachais agus na gCóras Sláinte UCD

A little about me!

UCD School of Nursing, Midwifery and Health Systems
UCD College of Health and Agricultural Sciences

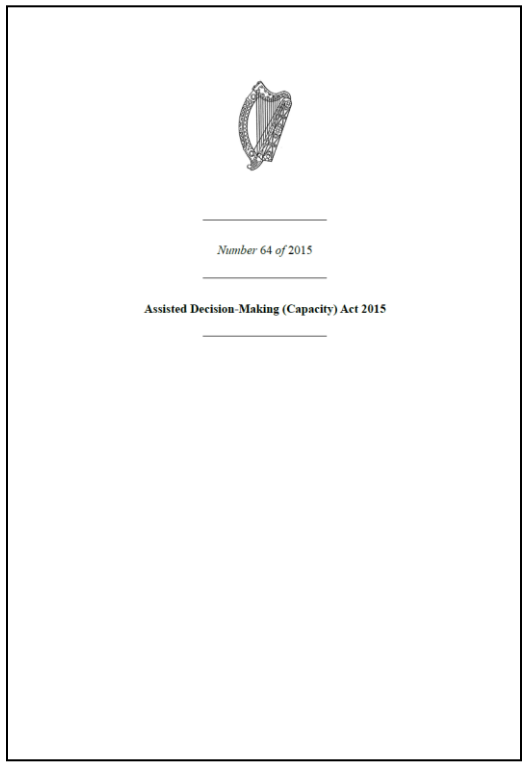
The largest and oldest University School of Nursing and Midwifery in Ireland, with over 1300 hundred undergraduate, postgraduate and research students.

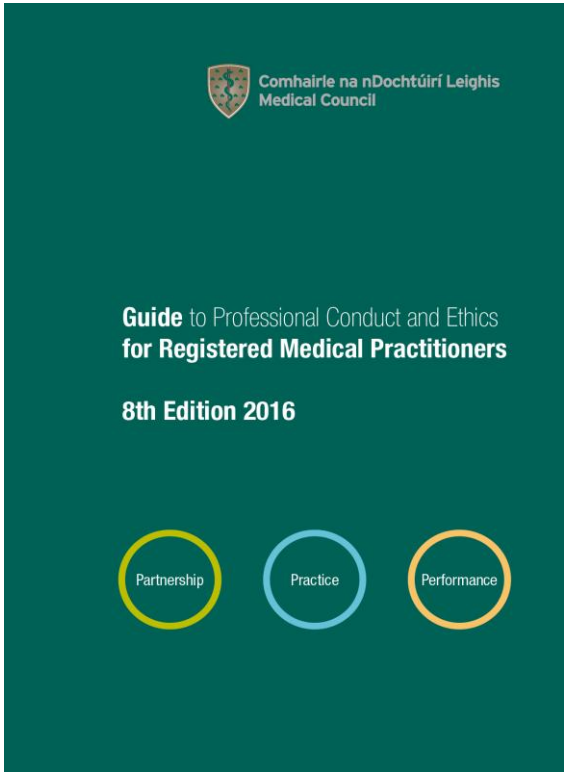
- When we hear the term Advance Care Planning what comes to mind?

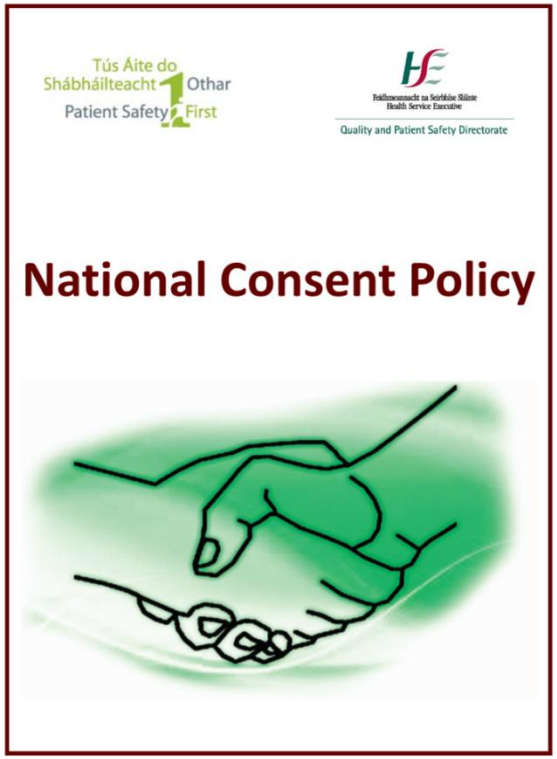
- We plan for the big and little things in life…
  - Birthdays, weddings, holidays, having a baby……
  - The future

- How often do we consider planning for the unexpected?
  - Accidents
  - Injuries
  - Ill health

Guides for practice in Ireland







Guide to Professional Conduct and Ethics for Registered Medical Practitioners (2016)

Chapter 3: 16.1

- Sometimes patients want to make plans for their medical treatment which will come into effect if they lose capacity in the future. Plans may include advance refusals of medical treatment or requests for specific procedures. You should do your best to help and support patients who ask for your assistance in writing an advance healthcare plan. You should ask patients with long-term conditions or conditions likely to result in their death or mental incapacity in the foreseeable future, if they have made an advance healthcare plan or directive. If a patient has lost capacity to make a decision, you should take reasonable steps to find out whether they have made an advance healthcare plan or directive.

Guide to Professional Conduct and Ethics for Registered Medical Practitioners (2016)

Chapter 3: 16.2

- An advance healthcare plan or directive has the same status as a decision by a patient at the actual time of an illness and should be followed provided that:
  - the request or refusal was an informed choice, in line with the principles [of consent];
  - the decision covers the situation that has arisen; and
  - there is nothing to indicate that the patient has changed their mind.

Guide to Professional Conduct and Ethics for Registered Medical Practitioners (2016)

Chapter 3: 16.3

- You are not obliged to provide treatment that is not clinically indicated for a particular patient.

Chapter 3: 16.4

- If you are concerned about an advance healthcare plan or directive, for example because of questions about the patient's capacity at the time of making the plan, or whether it applies in the current circumstances, you should make treatment decisions in the patient's best interests. In making such a decision, you should consult anyone with legal authority to make decisions on the patient's behalf, the healthcare team and the patient's family, if possible.

We need to consider planning ahead for those unexpected happenings……

- What if … you were diagnosed with a life limiting or a chronic condition like dementia?
  - It may take you a while to adjust to the news
  - You may decide that you want to plan ahead

Planning ahead for what exactly?

- Organising my finances
- Health: Advance care planning
- Choosing who will speak for you for health and personal care

- Planning Ahead
  - It’s about planning for the rest of your life…..

Planning ahead: An example of information, resources and support

- https://www.youtube.com/watch?time_continue=3&v=VYdy90dh7zg

Defining Advance Care Planning

- 'Advance care planning enables individuals to ***define goals and preferences*** for future medical treatment and care, to ***discuss these goals and preferences*** with family and health-care providers, and to ***record and review these preferences*** if appropriate' (Rietjens, Sudore, Connolly et al., 2017).

ACP - an inclusive process

- ACP is a process that includes:
  - Identification of values
  - Identification of goals and preferences for future health care
  - Discussion of goals and preferences with family and health-care providers
  - Documentation of preferences
  - Appointment of a proxy decision maker (where appropriate, applicable and legally enabled)

What needs to be considered when doing ACP?

- ACP should not be seen as a one time only conversation but rather it is an ongoing and continuous process and forms pat of current care planning
- ACP does not just focus on the physical domain but should concern itself and include with psychological, social and spiritual goals and preferences
- ACP happens at patients request and conversations are conducted at patients pace
- ACP happens with with those who understands patient's wishes if patient does not have capacity, with those who understands patient's wishes
- ACP is mindful of the patients best interests
- ACP is not limited to any particular patient group but is focussed on individuals with capacity to consider and identify personal goals and preferences for future health care
- ACP is documented and accessible when needed

Who is ACP for?

- Patient
- Family
- Healthcare professional

Who should help discuss ACP?

- Health-care professionals with ability and skills to talk about diagnosis, prognosis, death and dying

- Appropriate health-care providers are needed for clinical elements of ACP, such as discussing diagnosis, prognosis, treatment, and care options, exploring the extent to which goals and preferences for future medical treatment and care are realistic, and documenting the discussion in medical file

- A trained non-physician facilitator can support an individual in the ACP process

(Rietjens, Sudore, Connolly et al., 2017)

Why do ACP?

- To respect patient's wishes – and ensure they are respected even when the patient may not be able to articulate their choices
- To improve continuing and end of life care
- To ensure healthcare professionals and carers are clear and sure about the wishes and desires of the patient
- To reduce health care costs associated with inappropriate referral and admission to acute care centre, or continued advanced interventions which are potentially futile

Why not do ACP?

- Consistency of wishes
- Undermine doctor-patient trust
- Institutional agenda-cost
- Coping mechanism of patients

Consistency of wishes

- Patients were more likely to accept treatment resulting in certain diminished states of health, including pain, as time progressed and health deteriorated (Fried et al., 2006)

- Advance care planning can be used to establish a person's wishes about their care at the end of life and this increases the likelihood of their wishes being met (Abel et al., 2013; NHS 2011,2014)

Undermine Staff-Patient Trust

- Fear of over-aggressive treatment
- Fear of medical paternalism
- Duty of doctor to act in the patient's best interests

Institutional agenda

- Cost containment - frequent emphasis on withholding and withdrawing treatment with the intention to reduce costs

Advance care planning – some considerations

- Autonomy
- Functional capacity
- Informed decision
- Not obligatory
- Cannot oblige futile or unethical or illegal treatment
- The initiation of ACP (that is, the exploration of the individual's experiences, knowledge, personal values, and concerns) can occur within or outside of health-care settings

Advance planning considerations

- Rarely urgent – we need to consider ACP as a process over a number of encounters
- ACP conversations are fit for purpose - not so vague as to be useless
- Documented in such a way as to be available when needed
- Encourage engagement with family

When should we do ACP?

- Diagnosis of an illness in which there is likely to be loss of capacity
- Diagnosis of an illness, when there are likely to be complications needing urgent treatment for example respiratory failure in MND/ALS, cardiopulmonary arrest
- Disease progression indicators
- Hospital admissions

Diolch
Köszönöm
Sheun
Kasih
Toda
Mamnoon
Shnorhakalutiun
Hvala
Shokriya
Spaas
Mul
Ači
Gamsahapnida
Ngiyabonga
Xie
Dank
Takk
Cam
Kop
Salamat
Merci
Gra
Dankie
Grazie
Faleminderit
Dhanyavad
Khopjai
Kruthagnathalu
Dakujem
krap
ThankYou
kun
Arigatou
Dhonnobaad
Tack
ederim
Asante
Grazzi raibh
Gracias
Hvala
Blagodarya
Gomapsupnida
Kun
Shukriya
Hain
Dhan
Terima
Danke
Eucaristo
Enkosi
dank
daa

References and resources

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- http://www.letmedecide.org/

- https://www.advancecareplanning.org.au/individuals/what-is-advance-care-planning