Specialist Palliative Care
when you need help most

Advanced Care Directives:

A Medical Perspective

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Disclaimer

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  - Irish Committee for Higher Medical Training
  - Royal College of Physicians of Ireland
- Chairman, Irish Association of Palliative Care

- Speak in a Personal Capacity
- No Conflict of Interest

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Certainty? In this world nothing is certain but death and taxes.

Benjamin Franklin

Leading Causes of Death

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27,479 registered deaths in Ireland in 2006

- Circulatory diseases 42%
- Cancers 27%
- Respiratory diseases 16%
- Injury and poisoning 6%
- Other 12%

CSO 2006

Need for ACDs

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	Risk of Death
• Circulatory diseases	
• Heart Disease	New York Heart Classification
• Stroke	1 month/ 1 year survival
• Cancers	
• Common Cancers	5 Year Survival Rates
• Advanced Cancers	Palliative Prognostic Index
• Respiratory diseases	
• COPD	BODE index & CURB-65 Score
• Injury and poisoning	
• ICU Admissions	Early Warning Signs

Need for ACDs

An assumption ‘that every cause of death can be resisted, postponed or avoided’

Prof David Clarke

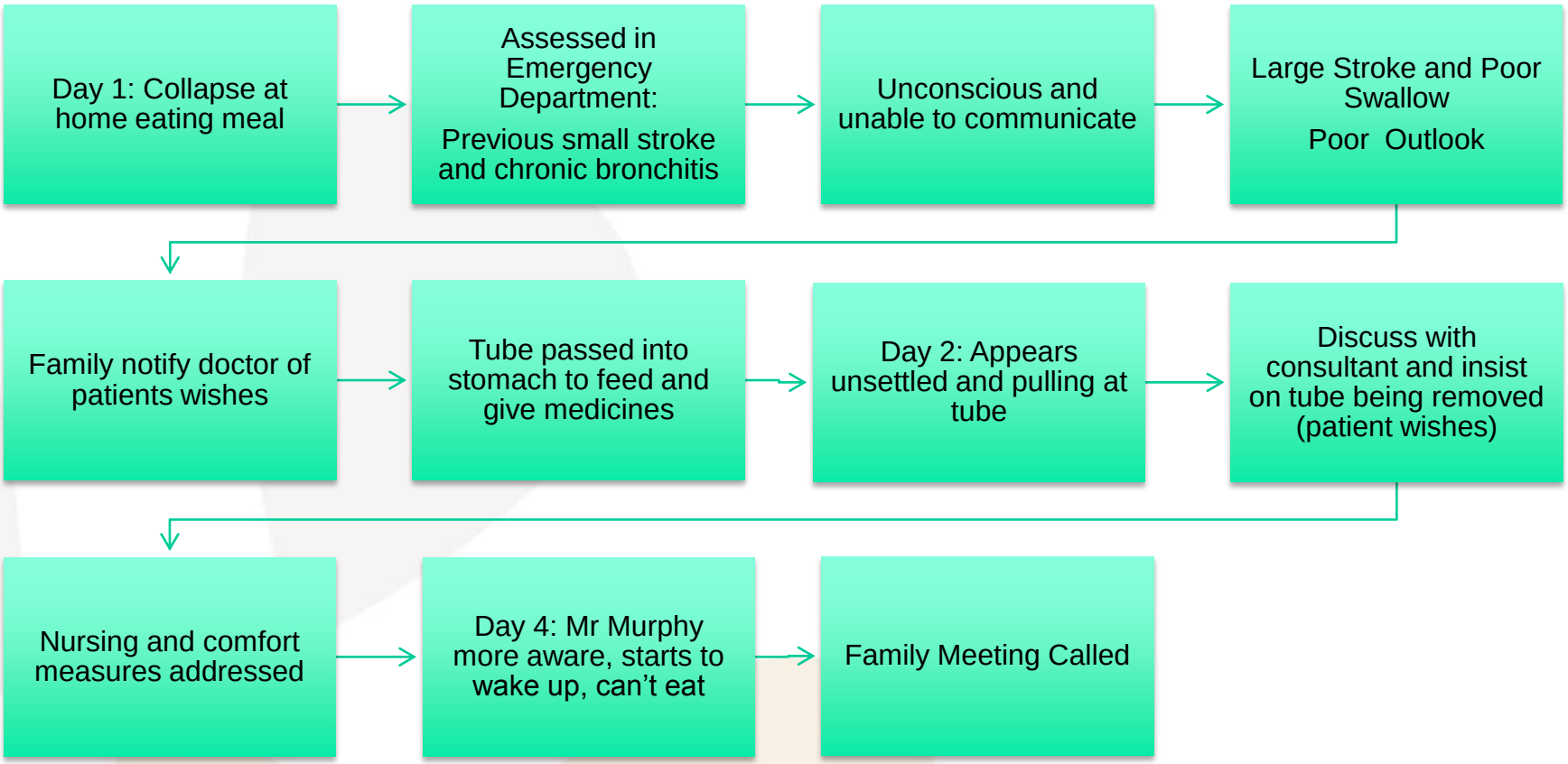
Visiting Professor of Hospice Studies, TCD

Death comes oftenest at night, especially in the small hours after midnight, when vital forces seem to be at their lowest ebb. In the very old, death often takes over from his brother, sleep.

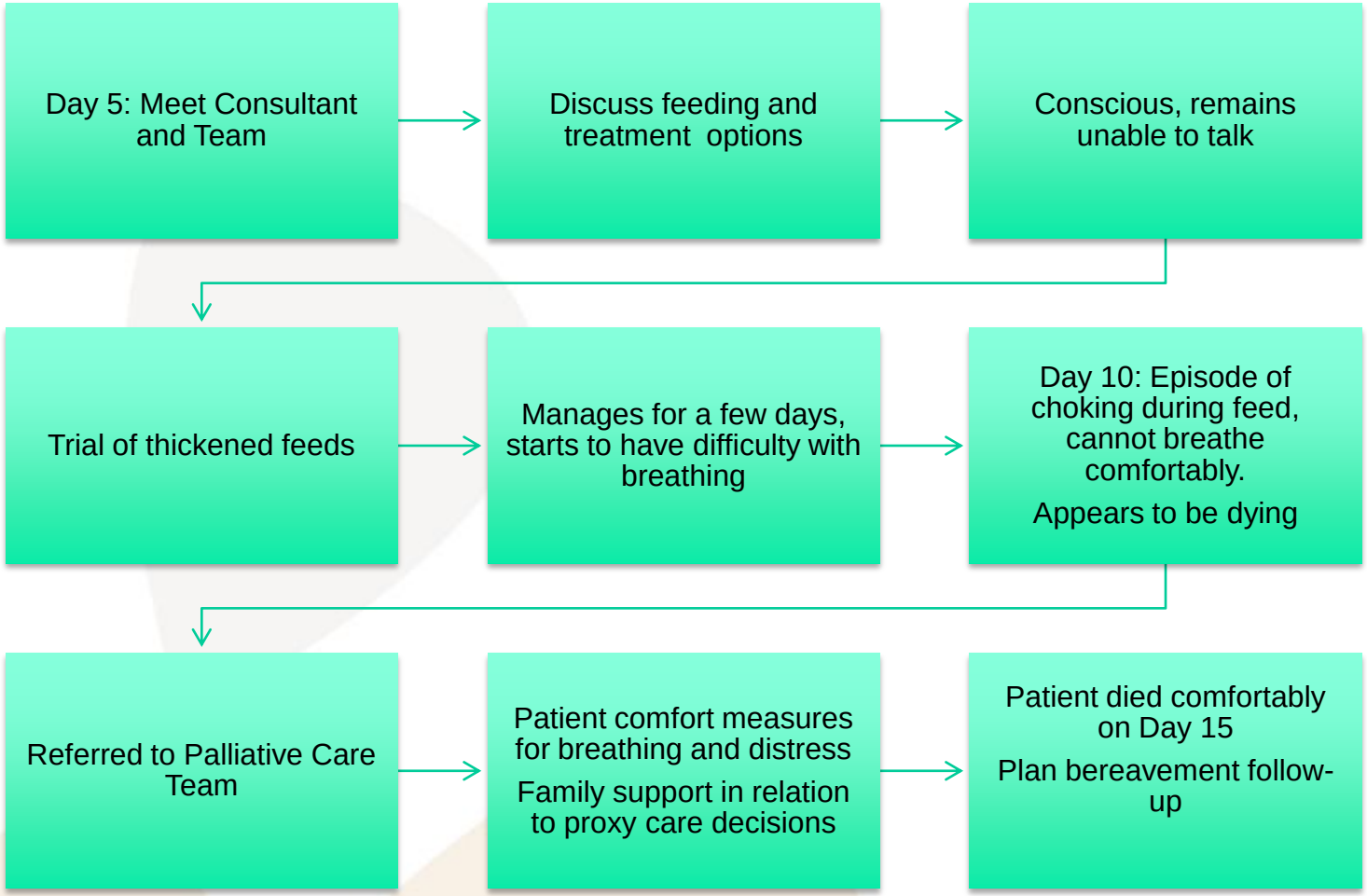
Richard Kern

The Care of the Aged

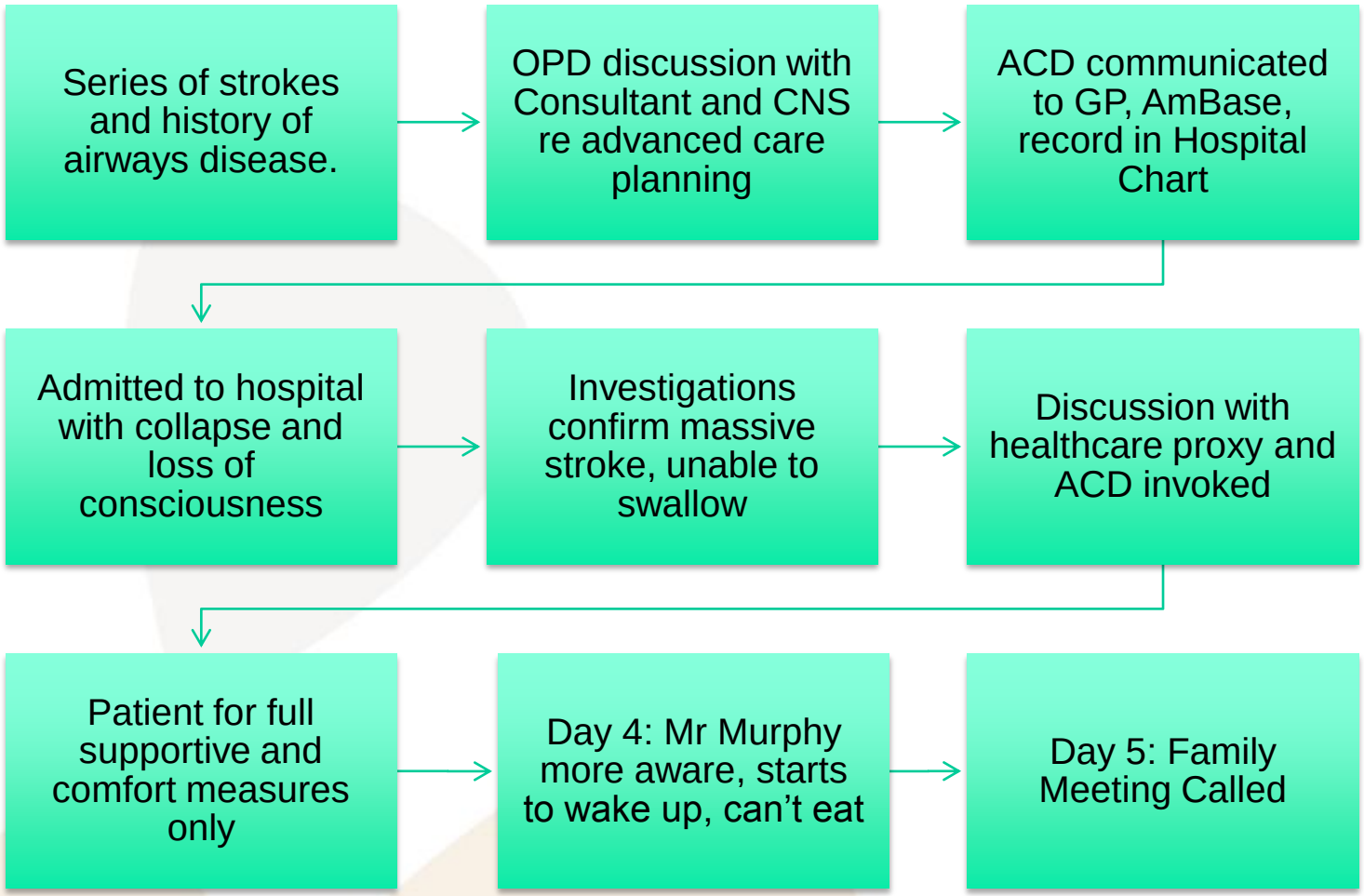
Mr. Murphy Age:70



Mr. Murphy Age:70



Mr. Murphy Age:70 Ver2



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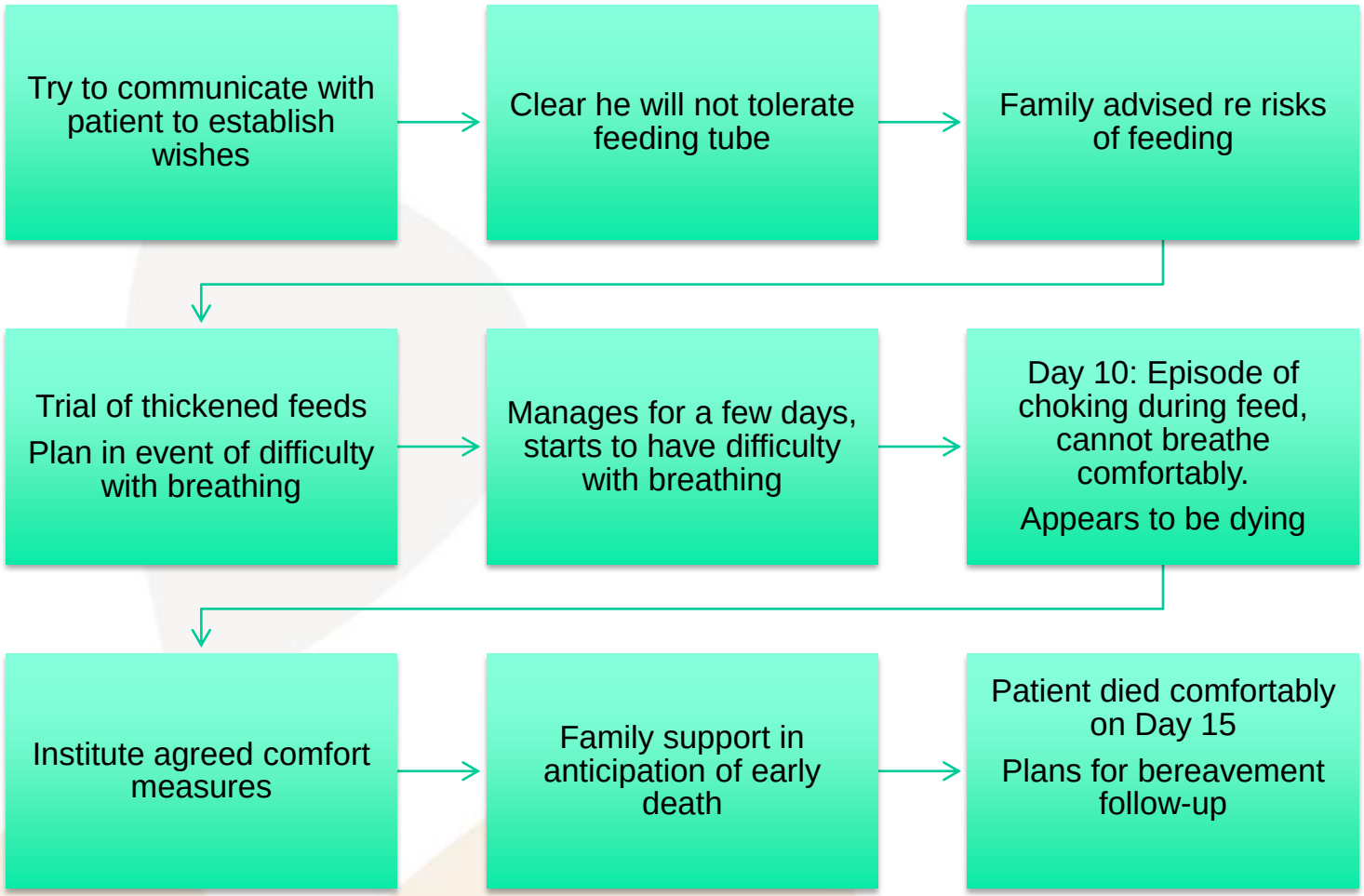

No National Guidelines

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- Bunracht na h-Eireann
  - Article 40.3
- Medical Council Guidelines
  - Competent adults can refuse treatment
- European Convention on Human Rights
  - Articles 3, 5, 8 & 9
- Human Rights Act UK (on medical decision making)1998
- The X-Case (Irl) – the right to die
  - Ordinary vs Extra-ordinary Care
- IAPC guidelines on Artificial Nutrition and Hydration

Absence of Guidance

- Experience
  - Specialist Palliative Care/Hospice
- Proxy Decision Making
  - Family surrogates judgment best
  - General Practitioner/Family Physician
    - Length of time known
    - Frequency of visit in last year
  - Physicians with no prior experience – very poor rating

Coppola KM
Arch Intern Med 2001; 161: 431-440

Absence of Guidance

- Procrastinate
  - Why don't patients and physicians talk about End of Life Care?
    - Education about EoLC
    - Counseling to help address concerns
    - System changes to facilitate communication
    - Physicians:
      - The patient has not been very sick yet
      - The patient isn't ready to talk about death yet

Curtis J et al
Arch Intern Med Vol. 160, June 12, 2000

Timing of Discussion

- Earlier is better
  - ACDs in Motor Neuron Disease
    - Clear preference by patients to have early discussion to allow accommodation to losses and make decisions when they are well

Corr B, Hardiman O

Masters Programme Underway

- Perspective changes with time
  - Acceptability of treatment resulting in diminished capacity increases with time
  - More likely to accept if decline is anticipated
  - Exception:
    - Treatment resulting in a state of pain

Fried TR et al

Arch Intern Med 2006; 166:890-895

Discussion with whom?

- 17.1 A competent adult patient has the right to refuse treatment. While the decision must be respected, the assessment of competence and the discussion on consent should be carried out in conjunction with a senior colleague.

- 22.1 For the seriously ill patient who is unable to communicate or understand, it is desirable that the doctor discusses management with the next of kin or the legal guardians prior to the doctor reaching a decision particularly about the use or non-use of treatments which will not contribute to recovery from the primary illness.

Medical Council of Ireland

A Guide to Ethical Conduct and Behaviour

Lost opportunities

The unbearable tragedy is not death but dying in an alien arena – separated from dignity, separated from the warmth of familiar things, separated from the ever present ministrations of a loving relationship and an outstretched hand.

Prof Norman Cousins
Prof of Medical Humanities, University of California
Human Options

Do Not Resuscitate

- Dissatisfaction with DNRs
  - A Study of Consultant Physician Practice
    - N=173
    - 21% had formal DNR policy in hospital
    - 49% unsatisfactory understanding
    - 67% Felt patients prefer not to discuss resuscitation
    - 43% Almost never discuss with patient
    - 32% Do not record reason if adult is competent

Ir Med J. 2006 Jul-Aug;99(7):208-10.

- Documentation of DNRs in an Irish Hospital
  - 4% of inpatients had DNR
  - Documented by Consultant/Registrar in main
  - 71% Discussed with family

Ir J Med Sci 2004 Vol 173: 99-101i

Communication

Clinicians must receive training in communication, not general communication skills but skills specific to the concerns of dying patients. Clinicians must be as comfortable in talking to patients about the dying experience as they are taking a history of angina

Emmanuel and Emmanuel 1998.

Plain English

- Doctor: “ I have looked at your tests today and there are signs that things are progressing so we do not think that you should have any more chemotherapy.
- Patient: “ Oh so what happens now then?”
- Doctor: “Well we just want you to come and see us if you develop any further problems with your breathing and we’ll treat those symptoms.”
- Patient: “Right then, well thank you very much doctor.”

Fallowfield et al

Palliative Medicine 2002;16 : 297 – 300.

Plain English

- Interviewer: “What did the doctor say to you?”
- Patient: “Well it’s good news really… the doctor thinks things are progressing so I don’t need any more 'chemo' and to come back if my breathing starts up again….getting breathless you know”

Fallowfield et al
Palliative Medicine 2002;16 : 297 – 300.

Autonomy

- “Autonomy is not just a status, but a skill, one that must be developed”
- “healthcare interactions rely upon assent, rather than upon genuinely autonomous consent”
- “throughout most of their medical lives, patients are socialised to be hetronomous, rather than autonomous”
- “at the worst possible time – when life and death consequences are attached to the choices, the paradigm shifts and real consent is sought, even demanded”
- Making an often traumatic situation even harder!

C. Myers 2004.

Questions on Commission's Consultation Paper

Tuesday 14th October 2008

- 6.06 The Commission provisionally recommends that an advance care directive cannot refuse actions concerning basic care.
  - Does that include Artificial Nutrition and Hydration?
  - Does it include supportive and palliative care?

- 6.09 The Commission provisionally recommends that a refusal to consent to treatment on religious grounds will in general (subject to constitutional considerations) constitute a valid advance care directive.
  - Will that include refusal of life-sustaining treatment for a minor?

- 6.10 **……**In the case of advance care directives refusing life-sustaining medical treatment, the Commission provisionally recommends that medical advice must be obtained for the advance care directive to be valid.
  - Will this be a ‘disinterested’ party
- 6.15 In the case of life-sustaining treatment, the Commission provisionally recommends that only written advance care directives are valid.
  - Will ICT be acceptable for people with disabilities?
  - What of people with literacy difficulties?

- 6.25 The Commission invites submissions on whether consequences and sanctions should follow if a medical professional fails to follow a valid and applicable advance care directive.
  - Will training will be provided to assist doctors in enabling patients to develop ACDs and when to invoke them?

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Cease then, and let me alone. For generations has this been (the sick man's) immemorial privilege, a privilege with vested rights as a deep seated-animal instinct – to turn his face to the wall, to sicken in peace and, if he so wishes , to die undisturbed.

Sir William Osler

Aequanimitas: Nurse and Patient

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everything can be taken from a man but one thing: the last of the human freedoms - to choose one's attitude in any given set of circumstances, to choose one's own way.

Dr. Viktor Frankl

Man's Search for Meaning