Implications of Forthcoming Capacity Legislation for Older People with Dementia

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Declaration of Interest

- Member of HSE National Steering Group for Assisted Decision Making (Capacity) Legislation

- Member of Ministerial Working Group on Implementing Advance Healthcare Directives

- Member of Codes of Practice writing groups

We didn't write the legislation!

All opinions expressed are personal

The ADM (Capacity) Act 2015

ADM (Capacity) Law - Not yet Commenced

- Passed by Oireachtas Dec 18, 2015
- Signed by President Dec 30, 2015

This Act shall come into operation on such day or days as the Minister may appoint …

- Most provisions – Minister for Justice
- Advance directives legislation – Minister for Health

2020 probably

Components

- General principles – functional approach to capacity
- Specific provisions- hierarchy of:
  - Assisted decision-making,
  - Co-decision making,
  - Decision making representative
  - Court (declarations, interim orders, reviews)
- Abolition of Wardship & revision of Enduring Power of Attorney system
- Director / Decision Support Service
- Advance healthcare planning
  - Advance directives (living will)
  - Appointment of designated healthcare representative

What's going on?

- Director of the Decision Support Service (DDSS) appointed (Áine Flynn) to supervise the operation of the Act.

- Writing of Codes of Practice has started. These Codes will 'flesh out' the law and determine how Act is implemented in practice. (A Code of Practice has a legal status and can be used by the Courts/ Regulatory bodies in resolving disputes/complaints).

- Draft guides for healthcare professionals well advanced

- Waiting for legal/DDSS opinions
  - When are court applications essential
  - Issues regarding AHDs

What's Not In

- Assisted Decision-Making (Capacity) Act **not** Capacity (Assisted Decision-Making) Act
- Diagnostic test – no provision that Act applies only if a diagnosis of, for example, dementia
- 'Best interests' determinations
- 'Capacity assessors' or any hierarchy of assessors

General Principles

Functional capacity

- Capacity - ability to understand at a **time** a decision has to be made, the nature and consequences of the **decision** to be made by a person in the context of available choices at that time.
- Time and decision specific
- Lack of Capacity – unable to
  - understand information relevant to decision
  - retain that information long enough to make a voluntary choice
  - use or weigh that information as part of the process of making the decision or
  - to communicate decision by any means

Elements of capacity ….

- Communicating a decision (by any means)
- Retaining information long enough to make choice
- Understanding information relevant to decision
- Using or weighing information as part of the process of making the decision (balancing or reasoning)

Complexity

(Gurrera et al, Am J Ger Psych 2007)

Reliability

How is capacity to be assessed?

- Information relevant to decision includes info about the reasonably foreseeable consequences of the available choices at the time or of failing to make the decision
  - *Individualised information and assessment*

- A person is not unable to understand information relevant to a decision if they are able to understand an explanation of it given in a manner appropriate to circumstances.
  - *Keep it as simple as possible*

- The fact that a person is able to retain information for a short period only does not prevent him/her from having capacity to make the decision
  - *Capacity is not a memory test*

Who will assess Capacity?

- Will depend on particular decision to be made
  - Generally it will be the person who needs the decision to be made
  - Consent to medical treatment – healthcare professional
  - Legal transaction - solicitor handling transaction
  - Everyday decisions - carer

- Formal processes may be required
  - If assessment is challenged
  - Serious decision – person must be able to justify findings

- Document: Justify findings based on criteria

It's not just doctors
(or psychiatrists or geriatricians)!

Guiding Principles

- Presumption of capacity unless the contrary is shown

- Person shall not be considered as unable to make a decision unless all relevant steps taken, without success, to help him or her to do so. (*Duty to maximise decision-making abilities – aids, support, best time and place, hearing aids, treat delirium*)

- Making an unwise decision is not indicative of being unable to make a decision

Interventions if Capacity Lacking

- There shall be no intervention unless it is necessary to do so having regard to the individual circumstances of the person (***not*** *'if we find incapacity we must do something'*)

- Any intervention should
  - Minimise restriction of person's rights and freedom of action,
  - Be proportionate to the significance and urgency of situation

- An intervener making an intervention in respect of a person shall in so far as is practicable (***not*** *'now we can decide what is best')*
  - Permit, encourage and facilitate the person to participate,
  - Give effect to the past and present will and preferences of the relevant person
  - Take into account the beliefs and values of the relevant person

Cognitive deficits only matter if relevant to decision at hand

- Standardised mental tests can not be used to determine decision-specific capacity
- They correlate with capacity judgements in general but are less help for individual patient
- Questions not clearly related to decisions - How are clock drawing or knowing the Taoiseach relevant?
- Liable to be misinterpreted as providing definitive evidence about capacity.

'But his MMSE is only 14!'

Specific Provisions

Scope of provisions

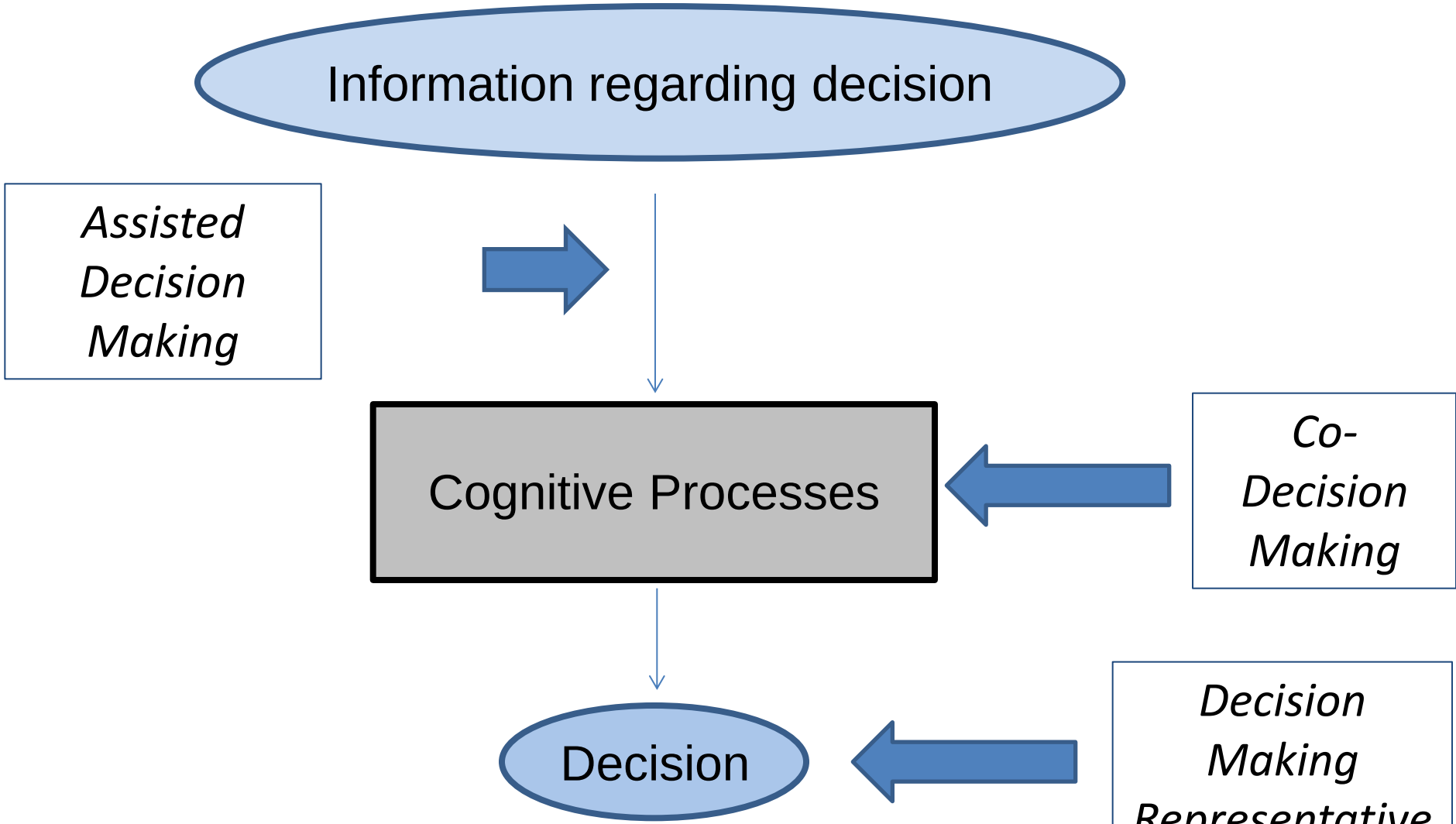
Person has capacity and makes the plans/ appointments

- Enduring Power of Attorney
- Advance Healthcare Directive including designated healthcare representative
- Decision-Making Assistant - Person has capacity but needs assistance

Person does not have capacity and did not pre-plan

- Co-Decision-Maker
  - Personal appointment with oversight
  - Can decide if assistance from co-decision-maker
- Decision-Making Representative
  - Court appointment
  - Person does not have capacity to decide
- Court (oversight if disagreements, seeking expert reports, declarations, interim orders, reviews)

Hierarchy for Decision-Specific Capacity



Who has legal authority to decide if person lacks capacity to make a decision?

Role of 'Next of Kin'? None!

- HSE National Consent Policy (5.6.1)
  - *"…no other person can give or refuse consent on behalf of an adult who lacks capacity unless they have specific legal authority to do so."*
  - Advises including '*those who have a close, ongoing, personal relationship*' in discussions and decision-making. Their role '*is not to make the final decision*' but to provide greater insight into the views and preferences of the person.

- *A false belief persists among healthcare staff (and the public) that consent should be sought from the 'next of kin'* [if a person can't consent]

- When person is dead, laws governing e.g. probate define order of priority (spouses, children, parents, siblings, nephews and nieces and so on).

- *This order of priority does not apply and does not confer any decision-making authority if a person is alive and lacks capacity to make a decision.*

(O'Keeffe, Donnelly & Madden)

Problems with 'next of kin'

- 'Next of kin' used to imply that others close to the person (such as a cohabitee or close friend) have no say or insight into person's preferences or interests.

- Delay in providing care while frantic efforts are made to contact distant uninvolved relatives.

- *'I'm the next of kin'! 'No, I am'!*
  - I'm the eldest
  - I live with Mammy
  - Mammy is leaving me the house / farm
  - I love Mammy the most
  - Mammy loves me the most
  - I'm recorded in the chart as next of kin/ contact person

Current system

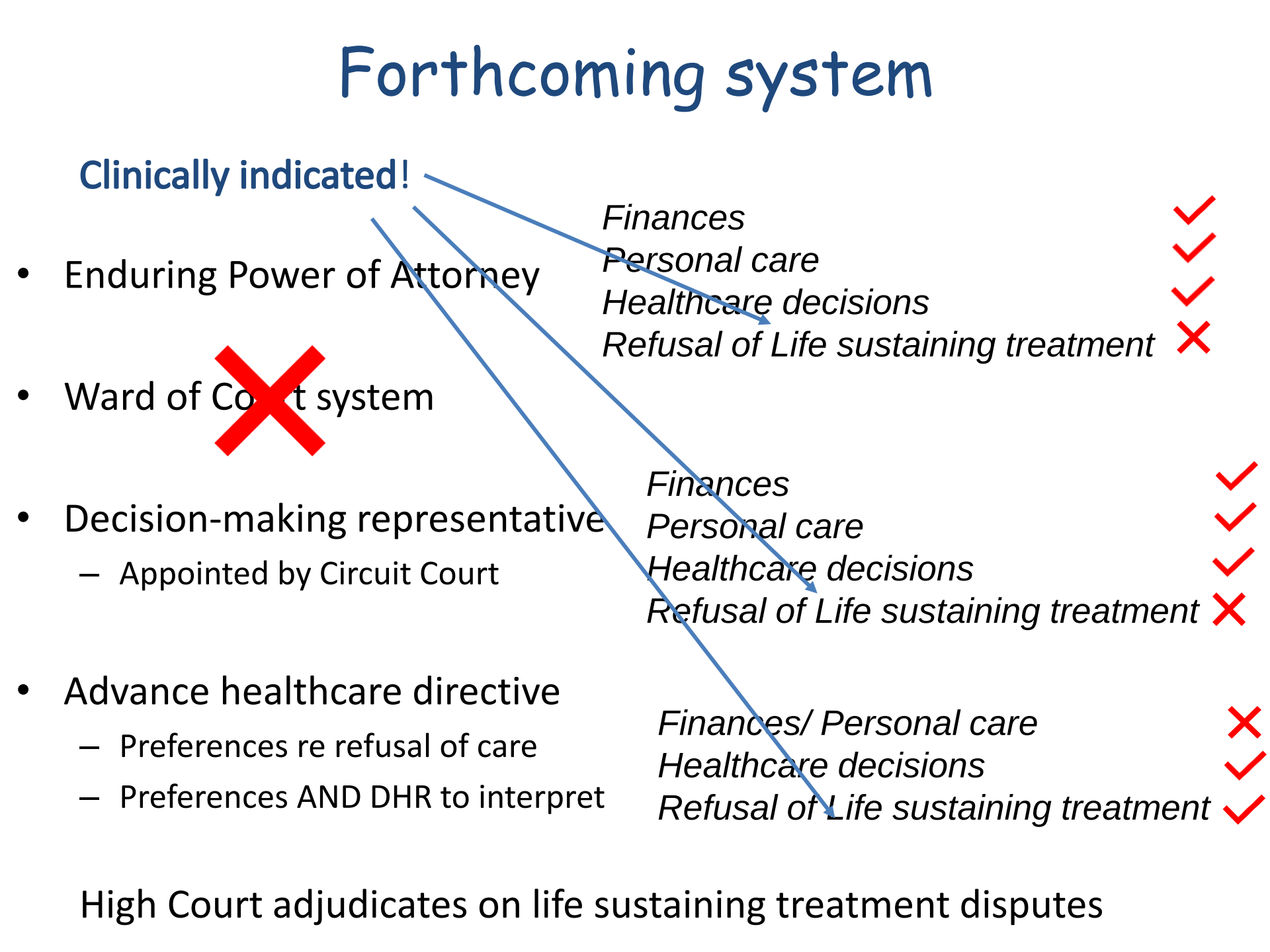
- Power of Attorney
  - Appointed by person (donor) to act if he/she is absent/abroad
  - Stops as soon as the donor lacks capacity
- Enduring power of attorney
  - Appointed by person to act if he/she lacks capacity
  - Only takes effect on the incapacity of the person
  - Must be registered with Ward of Court office
- Specific Court order
- Ward of Court system
  - Application to the High Court that the person is of unsound mind and incapable of managing their own affairs.
  - Personal care decisions made by 'Committee' (usually an individual close to the person)
  - Major healthcare decisions made by authority of the President of the High Court

Finances ✓
Personal care ✓
Healthcare ✗

Forthcoming system

Clinically indicated!

- Enduring Power of Attorney
- Ward of Court system
- Decision-making representative
  - Appointed by Circuit Court
- Advance healthcare directive
  - Preferences re refusal of care
  - Preferences AND DHR to interpret



High Court adjudicates on life sustaining treatment disputes

Risks to system

- Delays as staff try to figure out how and when to implement especially with regard to specific provisions.

- Expense if legal advice is sought and if a Decision-Making Representative is needed and those close to a person are unwilling or unable to fund it

- Enormous increase in requests for capacity assessments- psychiatrists, geriatricians, GPs

Risk of worse care

Fear of criticism.

- Nurse Nellie Nervous: *"He's making a foolish decision. There might be something wrong with him and I'd be criticised if I don't check it out. I know - I'll get a capacity assessment!"*

- Surgeon Scaredy: '*I've explained the risks and benefits and she consents to surgery. However, she is old and if something went wrong a relative might say that she didn't really understand the risks. She needs a formal capacity assessment*'.

Overly protectionist or paternalistic attitudes

- Capacity legislation means we can now make people do what we believe is best for them.

- Dr Nannie O'State:

  He's not doing what I advise.

  He seems normal but of course he can't be.

  There must some test that will be abnormal

  Damn! The CT brain and the MMSE are normal. Hmm.....

  I know! The neurologist/ geriatrician/ psychiatrist/ psychologist will have some test that will be abnormal. Hello, can you help?

Social workers took out court order to stop couple going on HOLIDAY because wife had dementia

By EMMA REYNOLDS
UPDATED: 17:39 GMT, 21 January 2012

An elderly couple were banned from going on holiday together after their local council said it was too risky.

In an astonishing example of the nanny state at work, Norman Davies and Peggy Ross were told by Cardiff Council that they could not go on the planned Mediterranean cruise, just days before they were due to leave.

Over-zealous social workers claimed Mrs Ross, who suffers from dementia, was in danger of wandering off or falling overboard.

Some Solutions

- Take presumption of capacity seriously! *A person shall not be considered as unable to make a decision merely by reason of making, having made, or being likely to make, an unwise decision*.

- No screening!

- When might incapacity (and capacity assessment) be considered?
  - An adequate 'trigger' exists such as a decision that seems particularly irrational or inconsistent with a person's prior preferences. AND
  - An intervention would be possible and appropriate in the circumstances

‘Capacity request’ from community

- 67 year old enormously fat diabetic
- Bed bound due to obesity
- Lives with son
- No psychiatric/ cognitive history but ‘not too bright’
- ‘Little insight into diabetes’, poor control
- Leg ulcers/ neuropathy
- Eating Crunchy Nut all the time – he demands them and son brings them to him

He should be in hospital/ in a home.

Giving him Crunchy Nut is a form of neglect by the son.

What if flood waters rose from nearby river or house went on fire?

- What capacity decision?
  - Decision to eat too much Crunchy Nut?
  - Decision not to take PHN etc too seriously?
  - Decision to remain at home

- What 'trigger' - None
  - He was always that way – not a change in personality/cognition to ignore PHN, etc

- What intervention? – None reasonable, proportionate or practical
  - Put him in a nursing home against his wishes for non-compliance?
  - A Circuit Court order forbidding Crunchy Nut

Deprivation of Liberty

- No specific protections – yet…
- Account must be taken of a person's past and present wishes, where ascertainable?
  - "Don't put me in a home" probably the commonest advance directive!
- Decisions should be the least restrictive of the person's rights and freedom of action
  - Involuntary detention for life?

Advance Healthcare Directives

Advance Healthcare Directives

- An advance expression of preferences concerning treatment decisions that may arise if the person subsequently loses capacity.
  - In 'writing' (includes voice and video recordings),
  - Two witnesses, at least one not immediate family member

- No need for medical discussion/approval or for capacity to make the AHD to be 'certified'

- Can **refuse** treatment (including for reasons of religious beliefs) even if that refusal
  - Appears to be an unwise decision
  - Seems not to be based on sound medical principles
  - May result in death

- No funding for an accessible Register. ?Responsibility on person to ensure accessible to healthcare staff

What Treatments do AHDs Cover?

- Treatment
  - Means an intervention that may be done for a therapeutic, preventative, diagnostic, palliative or other purpose related to the physical or mental health of the person, and includes life-sustaining treatment

    (Includes artificial nutrition and hydration)

- Basic care is not 'treatment' and therefore AHD is not applicable to basic care
  - Includes (but is not limited to) warmth, shelter, oral nutrition, oral hydration and hygiene measures

    (Pain treatment not regarded as basic care)

Designated Healthcare Representative

- Person can designate a named individual (or alternate) as a designated healthcare representative

- May confer on the designated healthcare representative the powers:
  - To advise and interpret what the directive-maker's will and preferences are regarding treatments
  - To consent to or refuse treatment, including refusal of life-sustaining treatment, based on the preferences of the directive-maker

Example

- Mary made an AHD and appointed her friend Susan as her DHR with power to refuse consent to life sustaining treatment on her behalf.

- Mary now severe dementia and is admitted with a severe chest infection. Susan tells staff that Mary is not for CPR/ventilation.

- Mary's only child, John, has just arrived from Australia to see his mother and demands that his mother should receive all treatment including CPR if required. He was unaware of the AHD and is Mary's closest relative.

- Staff inform him that Susan is the legal decision maker and that her refusal of treatment for Mary must be obeyed. (There was no obligation on Mary to inform her son of her AHD and there is no obligation on Susan to consult John).

Treatment Refusal

- **Legally binding**, must be complied with if 3 conditions met
  - The maker of AHD **now lacks capacity** to consent to treatment
  - The treatment to be refused is **clearly** identified
  - The circumstances in which the refusal of treatment is intended to apply are **clearly** identified in the AHD

- **A refusal of life-sustaining treatment** must be substantiated by an **explicit statement** that the AHD is to apply to that treatment even if his or her life is at risk

- A **request for** treatment in AHD is **not** legally binding but shall be taken into account during any decision-making process

What if an AHD refuses treatment in 'all' or in 'any' circumstances

AHDs: Potential Benefits

- Extends individual autonomy to when one lacks capacity
- Better end of life planning:
  - Doctors often fail to elicit patients' wishes and lives may be unduly prolonged by use of unwanted or futile medical treatment.
  - Encourages and facilitates advance discussion
  - 'Portable' end of life decisions across sites
- Designated healthcare representative:
  - Clear legal authority
  - Avoid different voices, e.g. if family disharmony
- Legal clarity for professionals
- Helpful if medical situation is plain, crisis is foreseeable and person has strong, specific preferences.
  - 'Right to die': Teresa Schiavo/ Eluana Englaro/ Irish Ward case
  - Jehovah's Witnesses and blood transfusions

AHDs: Potential Drawbacks

- Very far advanced AHDs
  - People underestimate QOL of their older, more disabled and cognitively impaired selves
  - Stability of preferences?
  - No mandatory revision time

- No ‘wriggle room’–can’t educate, discuss or debate with a document

- Misperception that AHD is the only way to plan end of life care
  - “If you don’t have an AHD, I’ll have to resuscitate you”
  - Advance care planning still relevant: not legally binding but morally important and should be respected

Will People Complete AHDs

- USA – 18% of general population

- Study of 17,000 deaths (Hanson, Arch Intern Med 1996)
  - 9.8% living will
  - More in white, educated, wealthy
  - More in chronically or terminally ill

- 50% of Jehovah's Witnesses had failed to maintain up-to-date Medical Directive cards (Watchtower)

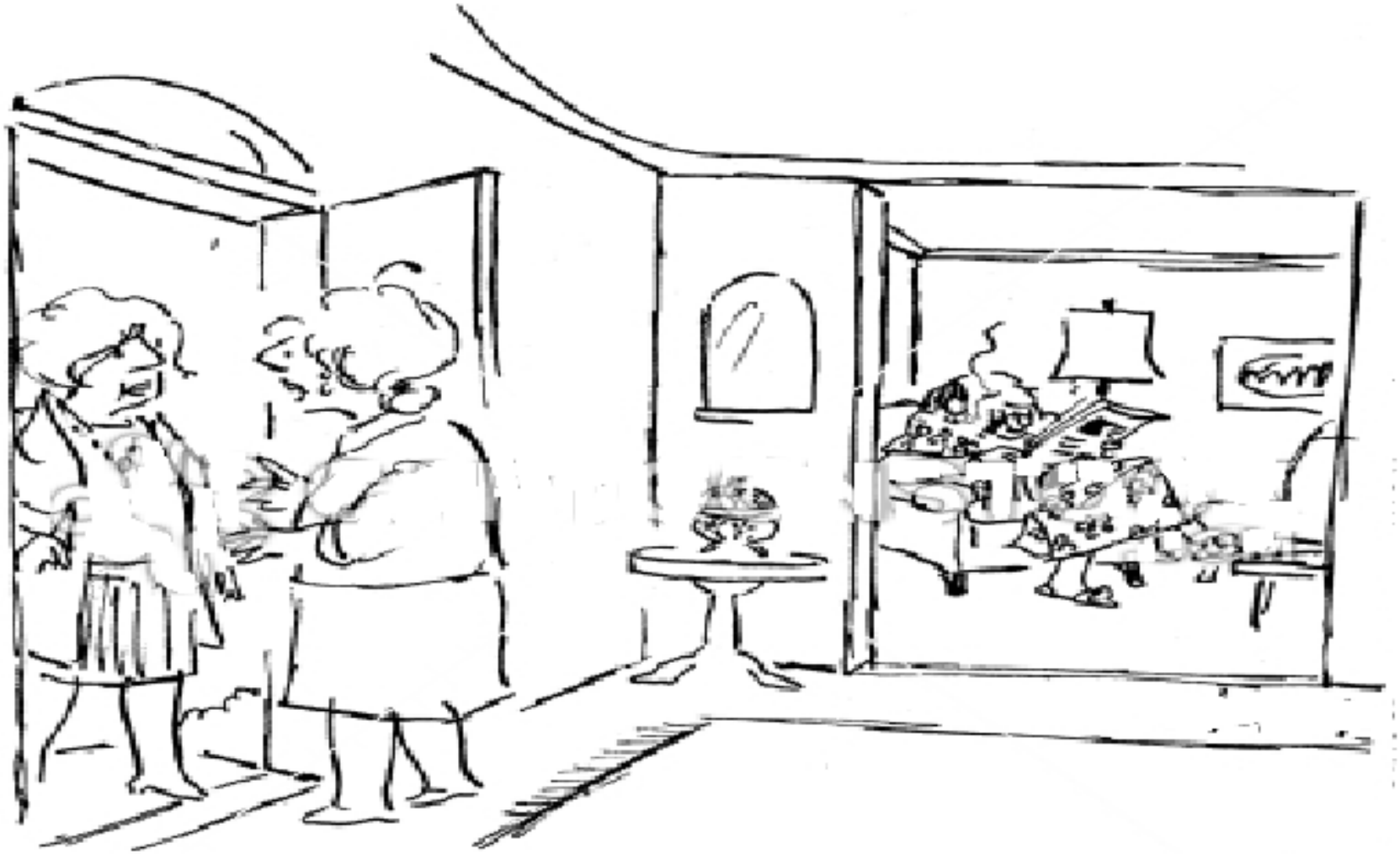
How will it all work?

It depends on….

- Whether people will make advance plans or directives and whether healthcare professionals will actively encourage such planning

- Codes of Practice to try to minimise need for court applications
  - Disagreement on presence of capacity
  - Disagreement on what to do is someone lacks capacity
  - Acting against the wishes of someone who may lack capacity

- How Courts interpret the Act



"I'm at my wit's end. Yesterday Paddy decided to become a transvestite."