Withdrawing, withholding and refusing life sustaining treatment

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Introduction

- Tension:
  - withdrawing, withholding or refusing treatment v preserving life

- Framework for today:
  - Overview of obligations to obtain consent
  - How these obligations play out:
    - For an adult (including role of Advanced Care Directives)
    - For a child (including consideration of the neonate)
  - Outline of tools available to assist

- SMS your questions/comments to Karen Berry on 0424 350 367
Introduction - tools

- Tools available to you include:
  - NSW Health Policy Directives and Guidelines
  - Hunter New England LHD Policy Documents
Consent

- Patient autonomy – before treatment, must have consent

- No consent = assault

- Inadequate consent = negligence

- Elements of consent – an individual must:
  - Be informed
  - Provide “valid” consent
Consent

- Defence – emergency

- Must be:
  - Incapable of consenting
  - Imminent risk
  - Not refused consent previously
Adults
Must be informed

- Individual must be informed of:
  - Their condition, including diagnosis and prognosis
  - Treatment options, including burden v benefit and likely outcomes

- Individual has a right to refuse receiving details about prognosis

- Don’t assume how much a person wants to know
Adults
Must be informed

- Collaborative approach
- Inclusive conversations and thorough documentation
- Senior treating clinician accountable for process
- Treating team acts in advisory capacity

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Adults
Must be informed

- Cyclic process:
  - Assessment
  - Disclosure
  - Discussion
  - Consensus building

- Update as patient’s condition changes
Adults
Must be informed

- Treatment plan must be documented:
  - Medical facts leading to decision
  - Persons involved in discussion
  - Statement of patient’s wishes where known
  - Goals of treatment
  - Details of treatment to be provided/withheld
Individual must provide valid consent:
- Voluntary
- Relate to treatment given
- Capable of giving consent—“competent”

If a patient is competent, their autonomy prevails over human life.

Main challenge can often be:
- Determining if patient is competent
- What to do if they are not
Adults
Determining capacity

- Adult patients are presumed to have capacity

- To show capacity:
  - understands general nature and effect of proposed treatment
  - Weighs up the consequences
  - is able to indicate whether he or she consents to treatment

- Rationality is not the test
  - Case of Re C – schizophrenia did not mean consent was invalid
Adults
Determining capacity

- Determining capacity is decision-specific.

- Capacity can fluctuate:
  - Effect of illness or medication
  - Timing
  - Language difficulties

- You may need to decide each time a decision is needed

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Adults determining capacity

- Practical tips:
  - Refer to the Advanced Planning Tools website
  - Ask open ended questions
  - Do not ask leading questions
  - Identify areas of concern
  - Ensure person being assessed answers the questions
Adults can refuse life sustaining treatment

- Competent, informed adults have the right to refuse treatment
- Treated differently at law from euthanasia and assisted suicide:
  - long as long as not done with the intention of ending person’s life
  - Even if actual effect may be to hasten death
- Extends to:
  - Providing appropriate use of analgesia and sedation
  - Artificial hydration and nutrition
  - Dialysis
  - Acting in accordance with Resuscitation Plans

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Adults
Can refuse life sustaining treatment

- *Brightwater Care Group v Rossiter*
  - Quadriplegic patient in care facility
  - Dependent on artificial feeding and hydration
  - Wanted carer to cease feeding and hydration
  - No issue of lack of capacity

- Court upheld Mr Rossiter’s wishes as long as he was “fully informed” of consequences
Lack of capacity – who else can consent

Who’s who in the zoo?

- If patient does not have capacity to consent the consult and seek consent to treatment from the “Person Responsible”:
  - Court or tribunal appointed guardian
  - Enduring attorney or guardian
  - Spouse
  - Unpaid primary carer
  - Close friend or relative

- May depend on terms of appointment
- Must act in best interests of patient

Order of preference
Best interests

- *Re Marion* – to consider:
  - Condition of patient
  - Nature of treatment
  - Reasons for treatment
  - Alternative treatment
  - Physical effects and associated risks
  - Medical, emotional and other welfare issues
  - Person’s past and present wishes, values and beliefs
  - View expressed by carers
Best interests

- *Cairns and Hinterland Hospital and Health Service v JT* (2014 QLD Supreme Court)
  - severe hypoxic injury secondary to diabetic ketoacidosis and cardiac arrest, unconscious state, sustained through artificial feeding and insulin
  - “assessed by reference…to what that person would, if able to express an informed view on it, regard as being in his or her best interests”

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Futile treatment

- Consent not required for futile treatment, **but** collaborative decision-making always best

- Futile treatment is not in “best interests” – consider:
  - No prospect of recovery
  - Affect on quality of life
  - Wishes of patient
Futile treatment

- Northbridge v Central Sydney Area Health Service
  - Criticism of hastiness of the diagnosis, the noncompliance with the hospital's own policies and inadequate communication between staff and family

- Messiha v South East Health
  - Unanimous medical opinion of three doctors (one independently sought) that the treatment would be futile and burdensome

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Adult
Advance Care Directives

- No specific legislation in NSW
- Valid when it:
  - Is made by an adult who is competent at the time
  - is made free from undue influences
  - extends to the situation at hand
- *Hunter New England Area Health Services v A*
- Position Statement on End of Life Care and Advance Care Planning published by the Australian Medical Association.
- NSW Health Report – Advance Planning for Quality Care at End of Life
- NSW Health Guideline – Advance Care Directives (NSW) Using
Advance Care Planning

- Figure 4: Sourced from *A National Framework for Advance Care Directives*, The Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers’ Advisory Council (2011)

- NB: NSW does not have statutory ACDs as there is no legislation pertaining specifically to ACD, as in some other States and Territories.
Children

- Children presumed NOT to have capacity to refuse treatment
- Courts can overrule child’s decision to refuse treatment
- Courts can overrule a parent’s decision to refuse treatment, or request treatment
- Consideration will be what is in the child’s “best interests”, in accordance with principles discussed above
Children
Consent to treatment

- Limited capacity to consent to treatment
- *Gillick v West Norfolk and Wisbech Area Health Authority*
  - Sufficient understanding and intelligence to fully understand treatment
- In NSW, child can consent
  - If above 16 years
  - If between 14 to 16, but rebuttable.
  - Not if under the age of 14
- Parents can override child’s decision if < 16 years
- *Re Janson* – could consent to hormone therapy
- No consent required if emergency
Children Refusing Treatment

- A child cannot refuse life sustaining treatment
  - Child does not have Autonomy
  - Sufficient understanding

- Sydney Children’s Hospitals Network v X
  - Patient was 17 years and 2 months
  - Jehovah’s witness
  - Refused blood transfusion
  - Acknowledged he would die without treatment
  - Court overruled patient’s decision
  - Court of Appeal agreed
  - High Court did not elect to hear the matter
Children Guardians to consent

- Obtain consent from guardian
- Whether withholding treatment in child’s best interest?
- Collaboration with guardian
- Can approach Court to make decision

Re Heather

- “oxygen therapy”
- Court overruled parents

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Resolving disagreements

- NSW Health Guidelines – End-of-Life Care and Decision Making
  - Family disagree with patient
  - Family want to continue unreasonable or inappropriate treatment
  - Patient requests cessation when inappropriate

- Guidelines recommend
  - Time and repeat discussions with family
  - Second medical opinion
  - Time limited treatment
  - Facilitation
  - Patient transfer
  - Guardianship Division of the NSW Civil and Administrative Tribunal
  - Legal intervention – option also available to family
In summary

- Patient autonomy and consent is paramount
- Consent must be valid
- Adult patients can refuse life sustaining treatment
- Capacity is presumed in adult patients
- Children cannot refuse life sustaining treatment.
- Guardians to consent – best interest of child
- Options for resolving disagreements – NSW Health Guidelines

- NSW Health website titled ‘The End of Life Decisions, the Law and Clinical Practice’ is very helpful for more information.
Hypothetical 1

- First infant of 32 year old diabetic mum
- Full Term
- Weight 4.2 kg
- Blood glucose initial result 2.1 mmol/L; second 1.8 mmol/L
- Baby not interested in the breast. Parents refuse artificial formula

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Hypothetical 2

- 4 year old girl has not been immunised by her parents. She is in a car accident where the vehicle is T-boned. The little girl suffers serious injuries including intraperitoneal, anterosuperior rupture/laceration of the urinary bladder.

- The girl requires laparoscopic repair of her bladder with post-operative ICU admission and antibiotics for prophylaxis.

- When the girl's parents find out about the antibiotics they object to the use of ongoing antibiotics and to the administration of the tetanus vaccine and immunoglobulin.

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41 year old patient with gestational diabetes presents to hospital at 38 weeks gestation. She reports that there has been minimal foetal movement the past 48 hours. She is booked for induction of labour in a fortnight.

CTG trace is difficult as the patient has a BMI of 40. However, there is evidence on the trace of periods of bradycardia.

The consultant recommends that the patient be prepped for emergency caesarean section. The patient is refusing to consent and is threatening to walk out of the hospital and go home.

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25 years old patient, MVA

Intubated & Ventilated, GCS 3.

Patient condition continues to deteriorate.

The patient's partner of two years and her parents arrive at her bedside. The parent's want the treating team to "do everything in their power" to save their daughter. The patient's mother has power of attorney for her daughter. The patient's partner seems to be more objective in receiving the prognosis from the treating team.

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80 year old patient with dementia is admitted to hospital with heart failure. His kidney function is worsening and he has had three admissions to hospital this year. His prognosis is poor and death is likely within the next year.

He made his son his attorney under an enduring power of attorney when his wife died. His son is listed as his next of kin in the clinical record but lives interstate. The patient looked after himself at home, but his granddaughter visits him regularly to check on him and helps with the groceries.

His kidney function has deteriorated to the point where he urgently needs dialysis.

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Patient has stage IV cancer and a poor prognosis (wouldn't wake up after being in ICU).

Patient continuing to receive chemotherapy.

The patient has expressed the wish to staff and it is documented in the notes that he wants to be resuscitated/intubated/taken to ICU if he goes into respiratory failure or has a cardiac arrest.

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