



“What they didn’t tell you about CPR and PEG feeds”

End of life decision making and clinically ineffective medical treatment.

Richard Polkinghorn (BSW, LLB, M Hlth M Law)
Advocate / Guardian – Victorian *Office of Public Advocate*
(Email: richard.polkinghorn@justice.vic.gov.au)

& Associate Professor Graham Schmidt (MBBS, FRACP, MRCP (Lond), FRCP (Edin.))
Gastroenterologist and Clinical Leader, *Respecting Patient Choices Program*, Eastern Health Network – Melbourne.

March 2007



2 - Program / Overview of Presentation

- 1. Legal & Ethical principles**
- 2. Macro-Ethical Issues**
- 3. Micro-Ethical Issues**
- 4. Cardio-Pulmonary Resuscitation (CPR)**
- 5. Percutaneous Endoscopic Gastrostomy Feeding (PEG's)**
- 6. Summary Points & Recommendations**

3 - Legal Principles

1 - Consent & Human Rights

- Patient consent to medical treatment is a basic human right.
- *“It exists notwithstanding ... the choice...(being)... **rational, irrational, unknown, or even non-existent**”*
- A competent patient’s request must be heeded, even when such **inaction will result in the patient’s death.**
- The **right to self-determination** (concept of **human dignity**) is held more important than the ‘**sanctity of life**’
-
- The *Medical Treatment Act 1988* (Vic) respects this right to self-determination and provides for a charge of **Medical Trespass.**
- Valid consent can be oral, in writing (as for most surgical procedures) and implied.
- **Genuine emergencies** are the **only exceptions** to these rules.



4 – The Doctor – Patient Relationship

- Informed consent is the **centerpiece** of the doctor-patient relationship.
- Difference between **going through an empty ritual** to having the **real power** to affect the outcome of the process.
- Critical to the process of informed decision-making is the provision of **adequate information**
- The patient (family) **cannot demand a particular treatment**. Rights are restricted to reasonable care and a right to refuse treatment.
- In the absence of such fully informed consent treatment is unlawful.





5 - Informed Consent and Disability

- Legal and moral **presumption of competence. ID or Mental Illness does not automatically signify incompetence.**
- The **quality and quantity of the information** is critical. No authority to give less information to the disabled.
- The issue of '**therapeutic privilege**' ("TP") often arises in matters of end-of-life decision making.
- The "TP" **test** involves **substantial risk of serious harm**. Not sufficient that the patient might be alarmed or distressed, or refuse consent.



6 - Informed Consent and Disability (slide 2)

- Patients are more likely to accept adverse outcomes if they and their families have **shared the decision making**.
- Guardians and attorneys have a **statutory right to necessary information**.
- Ignoring these ‘**micro-ethical**’ issues could **render the process irrelevant**.
- *Hastings Centre Standards* require that no one in the modern world should have to **live longer in the advanced stages of Dementia** than they would have done in the pre-technological era.
- Further, *Hastings Centre Standards* require that the **more advanced the Dementia, the more legitimate it is to overturn the usual bias in favor of treatment**.



7 - Competence Test for Treatment Refusal.

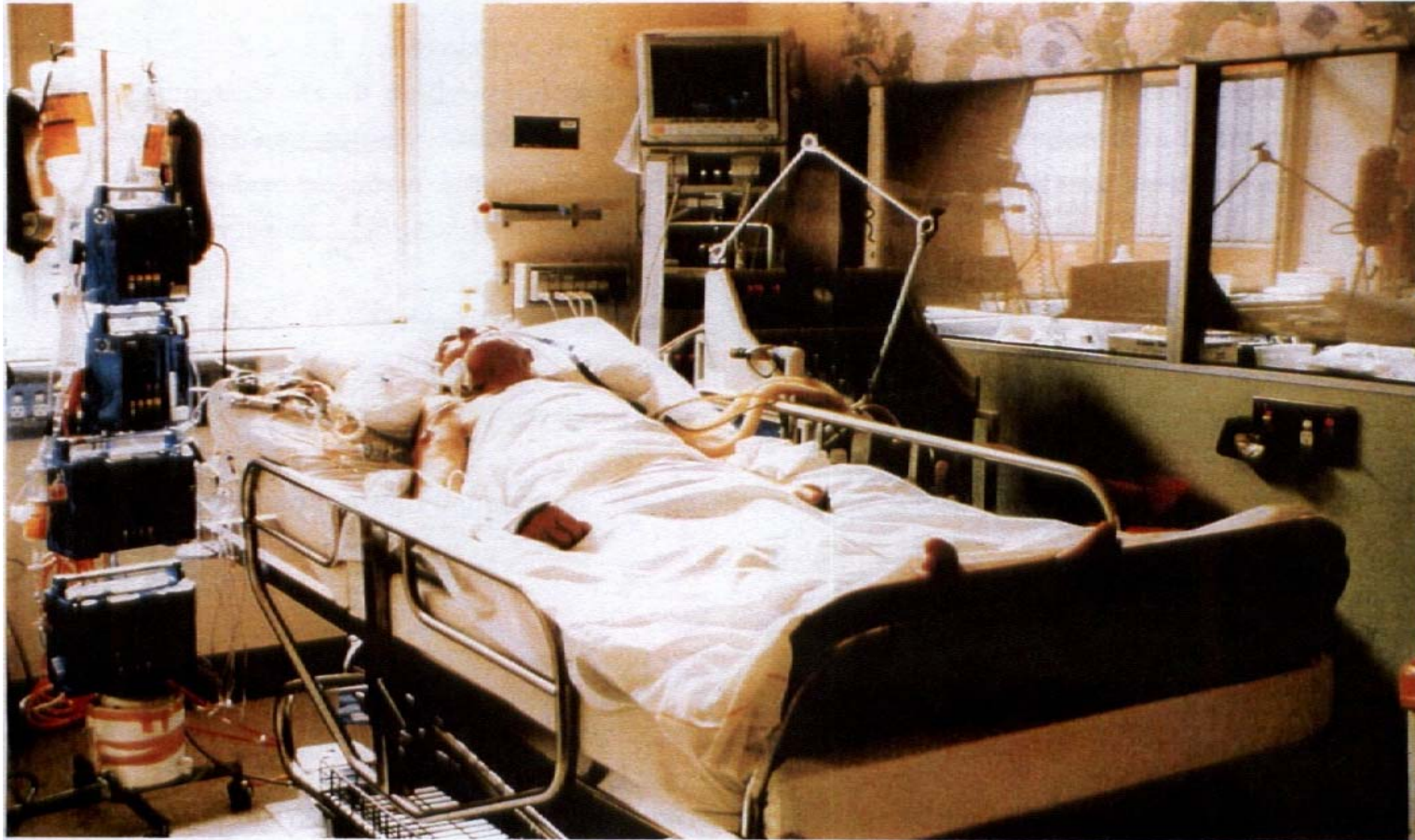
- Most common law jurisdictions have a “**functional test**” of **competence**. Versus. ‘**outcome approach**’ & ‘**status approach**’.
- A single ‘**functional test**’ is then **applied more rigorously** in the context of more serious or life - threatening treatment refusal.
- The level of capacity should not depend on the consequences of the decision. Instead required standards of evidence be placed on sliding scale.



8 - Test of Competence in “Re C”.

- Leading **English case *Re C (1994)* defined capacity** as understanding “the nature, purpose and effects of the proffered treatment”.
- The mechanics of this test of understanding are split into three stages:
 - **comprehending and retaining** treatment information,
 - **believing** the information, and
 - **Weighing it** amongst other factors to **reach a decision**.
- People with a life - long disability should be given this test in a way that optimizes their performance.
- Cameron Stewart provides an **excellent review** of this issue.

9 - Futile Care





10 - Futile Care

- A patient / family cannot **demand treatment that is not clinically indicated.**
- There is **no ‘duty of care’** or legal obligation to provide treatment **not clinically indicated.**
- “**Futile treatment**” cannot achieve its **physiological aim** and / or the **burdens of treatment** outweigh the **benefits** for a particular patient.
- In *BWV* Justice Morris held that treatment is ‘**futile**’ if it is not fulfilling a **medical purpose.**
- **Distinguish Euthanasia** – When in doubt or information of end-of-life wishes is lacking, the **default position** is always the **preservation of life.**
- An **enhanced duty of protection** exists for the most vulnerable (e.g. unconscious)
- Frequently **CPR** and **PEG** are applied in circumstances where they are **futile** and **not clinically indicated.**

11 - Futile Care vs. Futile Life Conundrum

- Frequently professionals in the area confuse a **'futile life'** with **'futile' medical intervention**.
- Doctors should not make **ill-informed estimations of a person 'quality of life'**, often on very limited information and conclude that treatment is 'futile'.
- Instead Doctors are required to decide in the context of a particular patient if a **particular medical intervention is futile**.
- Medicine works in probabilities and some areas of **diagnosis are uncertain**. Reference to **specialist opinion** and professional Guidelines (protocols) is essential.
- Various Supreme and High Court rulings have insisted on a basic re-statement of these fundamental principles.



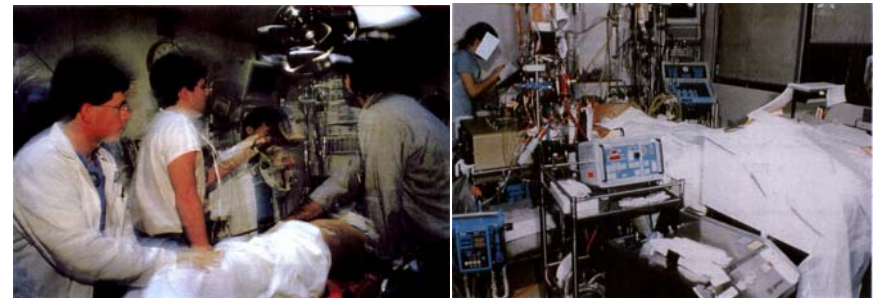


12 – Key Points

- Once admitted to hospital, staff come under a **positive ‘duty of care’ to provide care** for a patient.
- The ‘duty of care’ will normally require the provision of **CPR and insertion of PEG if clinically indicated**. However this **duty is not absolute** and there are **exceptions**:
 1. The duty does not **override a competent patient’s refusal** of treatment.
 2. Incompetent patients where it is **not considered in their ‘best interests’ to be kept artificially alive**.
 3. Patients in a non-responsive (NRS) or persistent vegetative state (PVS)
- When **uncertain about the effectiveness of treatment, treatment should be provided**. It can then be withdrawn, if inappropriate or not beneficial.
- There is **no moral or legal difference** between withholding or withdrawing treatment. However **emotionally and psychologically** the two are very different.

13 - Macro-Ethical Issues

- Nowhere are the **profound changes to the practice of modern medicine** more apparent, than in the practice of **CPR and PEG feeding**.
- Nowhere are the potential benefits of '**evidence-based medicine**' more conspicuous by their **absence**.
- The practice of medicine is often driven by the '**seduction**' of **high technology**, even where treatment is futile and burdensome.
- The community now enjoys a much **higher standard of education**.
- However not all of this information is accurate and certainly there is considerable "**misinformation**".



14 - Macro-Ethical Issues (Cont..)

- **Misinformation** in TV programs like “ER” and “Medical Emergency” leads to **unrealistic expectations** and **misunderstanding of critical issues**.
- ‘**Seduction**’ of the technology itself and the **need to do something**, leads to a much **pressured (often emotionally charged)** ‘**crucible**’ for decision-making.
- Frequent resort to the ‘**sloganism of starvation**’ in reference to the withdrawal of artificial nutrition and hydration (PEG).
- The well publicized criticisms of the Victorian Public Advocate in the “**BWV**” **case** illustrate this process.
- Likewise the frenzied **American battle pertaining to Terri Schiavo**, over **14 years** one of the longest in history.



15 - Micro-Ethical Issues

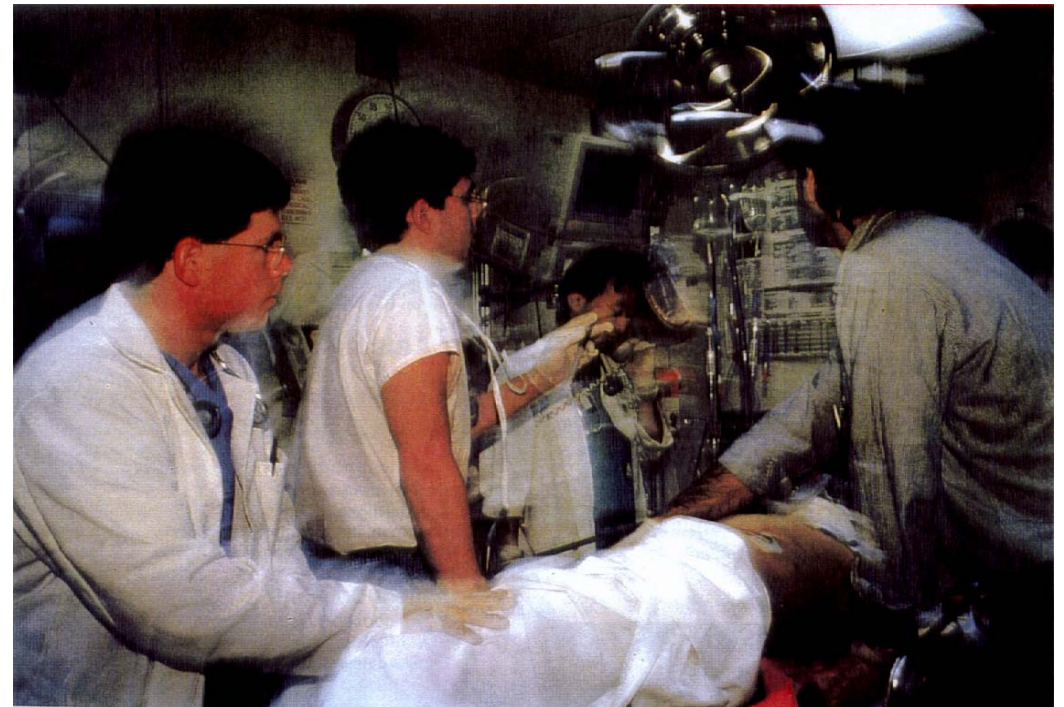
The concept of 'force feeding' or treating incompetent people who cannot express their wishes is an affront to every known human right.

- Misinformation and human factors create a **pervasive undercurrent on everyday clinical practice** and human rights.
- **Resuscitation and PEG placement** has moved from selective use on appropriate patients, to **default use of a more indiscriminate and widespread nature. Profound implications for the human rights** of very vulnerable people / Families.
- **Resuscitation and PEG placement** are not seen as an active intervention requiring informed consent. Rather the **'path of least resistance'** with little consideration to the likely medical outcomes.
- **'Misinformation'** in the community and the **special emotional connection** between food and nurturing, fuels the mistaken belief that the withdrawal of nutrition equates with **death by starvation**
- For the subjects of this paper, (namely **Frail** elderly people (defined as 65+ years), with multiple organ failure and elderly patients with severe dementia), the **outcomes are especially poor and disturbing.**



16 - Cardio-Pulmonary Resuscitation (CPR).

“Tragically, despite four decades of overwhelming research evidence, the indiscriminate use of CPR remains the standard response to a cardiac or respiratory arrest ... regardless of the underlying illness”



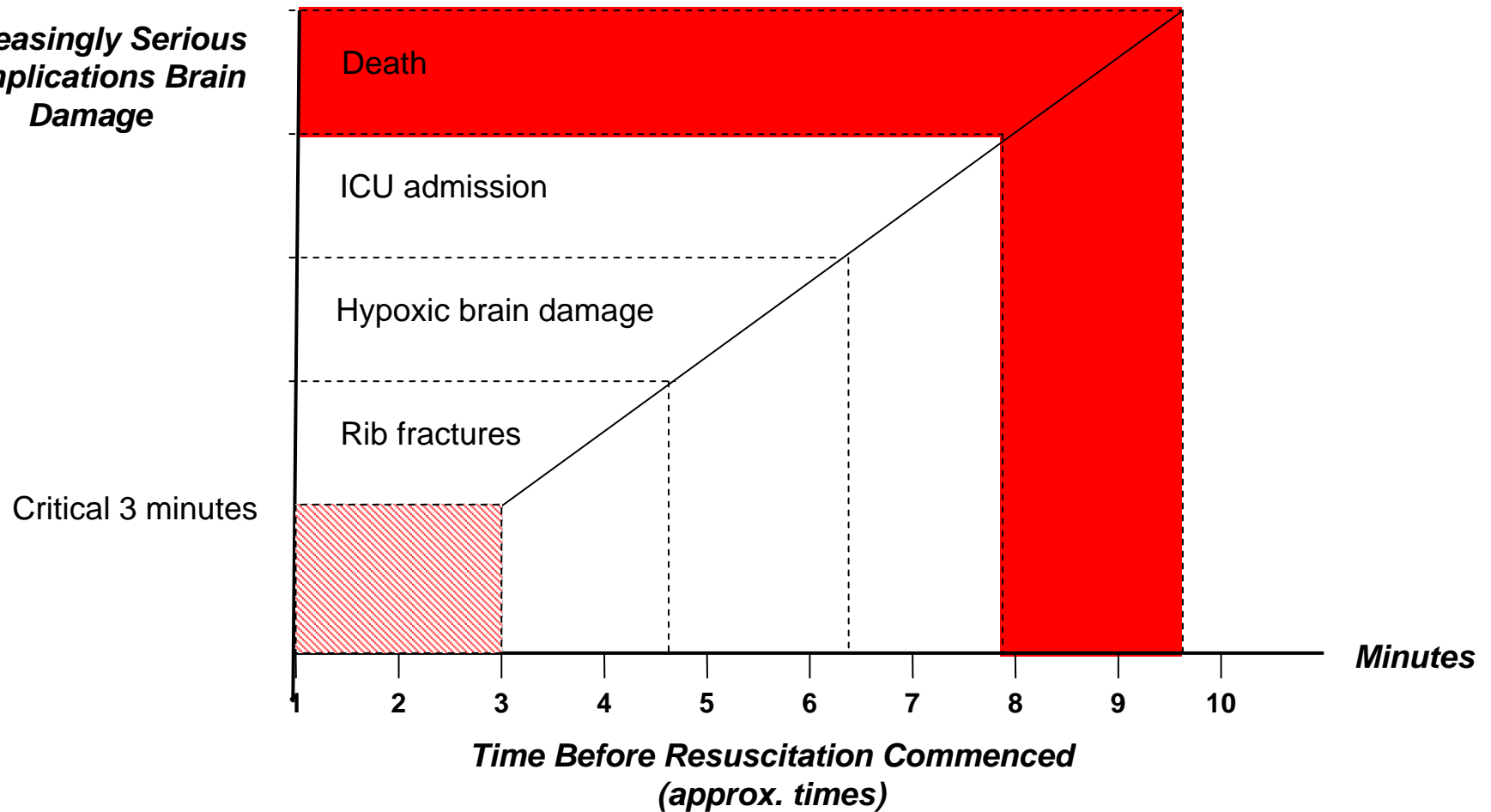
17 - CPR – What is it?

- **CPR** was developed in the 1960's as a **treatment for cases of sudden, unexpected cardiac or respiratory arrest.**
- **CPR** includes **mouth-to-mouth resuscitation, chest compression, bag-and-mask ventilation, intubation and defibrillation.**
- Following several **decades of research**, there is now clear evidence that while some people will benefit from this intervention, for many others there is **no benefit and potentially significant harm.**
- **Common serious complications** include **rib fractures, lung punctures, and prolonged stays in Intensive Care Units (ICU's).**



18 - Complications of CPR

**Increasingly Serious
Complications Brain
Damage**



“Survival from a Cardiac Arrest decreases between 7-10% each minute Defibrillation is delayed.”

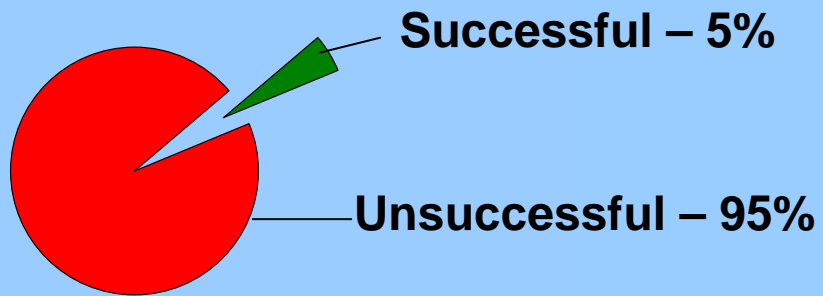
19 - CPR – “TV” Success Rates.

- 75% survived an arrest
- 67% survived until discharge

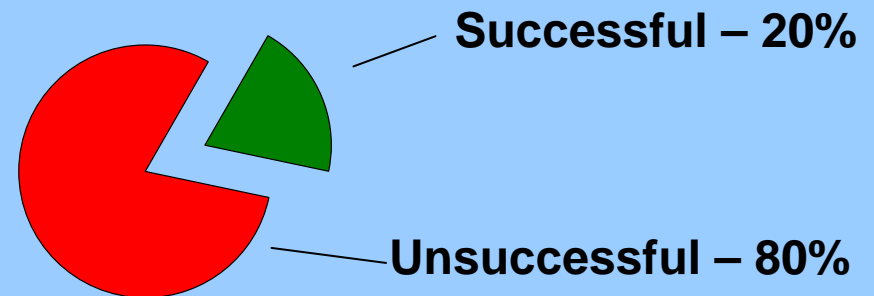


20 - CPR – Actual Success Rates

Frail Group



Non-Frail Group





21 - CPR – The Research Evidence

- Since 1960, the reported **survival rates for CPR vary from 5 % to 23 %.**
- Data for the **Frail elderly group (over 65 years), with multiple organ failure or severe dementia** (the subject group of this paper), shows **very few survive.**
- Indeed, for the **Frail elderly group** with multiple organ failure, **CPR is not only generally unsuccessful** but also **inappropriate.**
- Research shows the **vast majority (69 %)** of resuscitated hospital patients **die secondary to anoxic brain damage.**
- **Severe hypoxic damage to the brain** and other organs results in further invasive treatment (ICU care). Disturbingly a **small number of CPR survivors are left in a “chronic vegetative state”.**
- More importantly, the **length of survival of patients who were initially resuscitated**, but died before discharge, found that they **lived an average of 2 to 14 days, usually in an ICU.**



22 - CPR – Who should get it?

- Resuscitation should not be seen as a **choice between life and death.**
- When **put in these terms everyone would select Resuscitation.**
- **Resuscitation is a medical intervention similar to any other requiring 'informed consent' and a determination that the benefits outweigh the burdens.**
- Resuscitation is most effective in those **healthy individuals where the collapse is observed and effective resuscitation is commenced immediately.**

23 - CPR – Who shouldn't get it?

- Doctors must balance the **duty to protect life**, on one hand, with the **duty not to cause inhumane or degrading treatment** on the other.
- Resuscitation is **clinically futile** in the **Frail Elderly group with a past history of multiple organ failure, serious stroke and / or severe dementia**.
- Resuscitation is **clinically futile** in people with **advanced Cancers**.





24 - Conceptualizing End-of-life Decision-making.

“Doctors should ... anticipate the possibility that end-of-life issues ... adopt an open and frank approach to talking about them... ‘planning the course of the illness’ ... ”

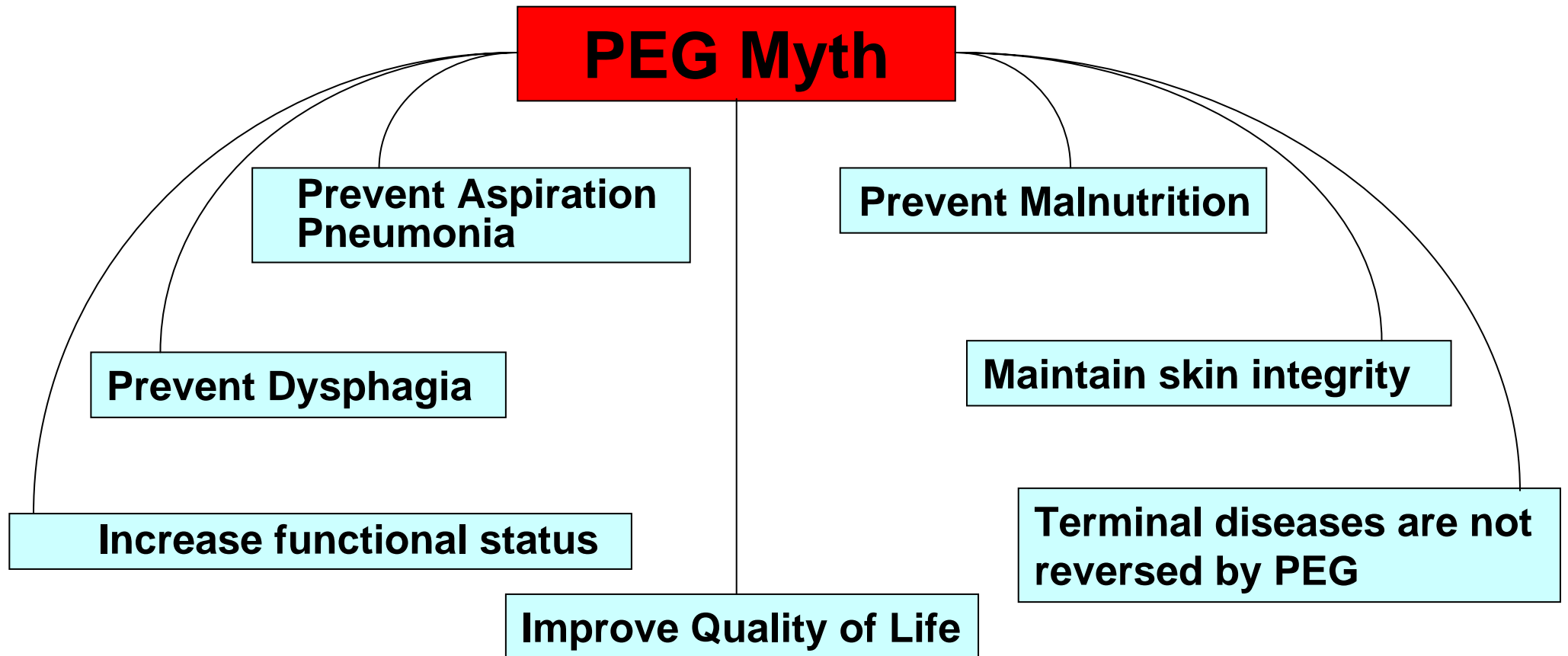
- Early and skilled discussion with the patient / family of end-of-life issues and informed consent to treatment are **critical**.
- It requires a frank discussion of the medical interventions (the many invasive, painful and often dehumanizing procedures) planned that are in effect **futile**.
- A No -CPR Order should not be equated with abandonment and the withdrawal of all treatment.
- A No-CPR Order should **not automatically** carry implications or prejudice other forms of treatment. For example, removal of a “*Chicken bone* lodged in a patient’s throat”.
- The choice between resuscitation and not-for-resuscitation **should not** represent an ethical choice between ‘preserving life’ and ‘allowing to die’.



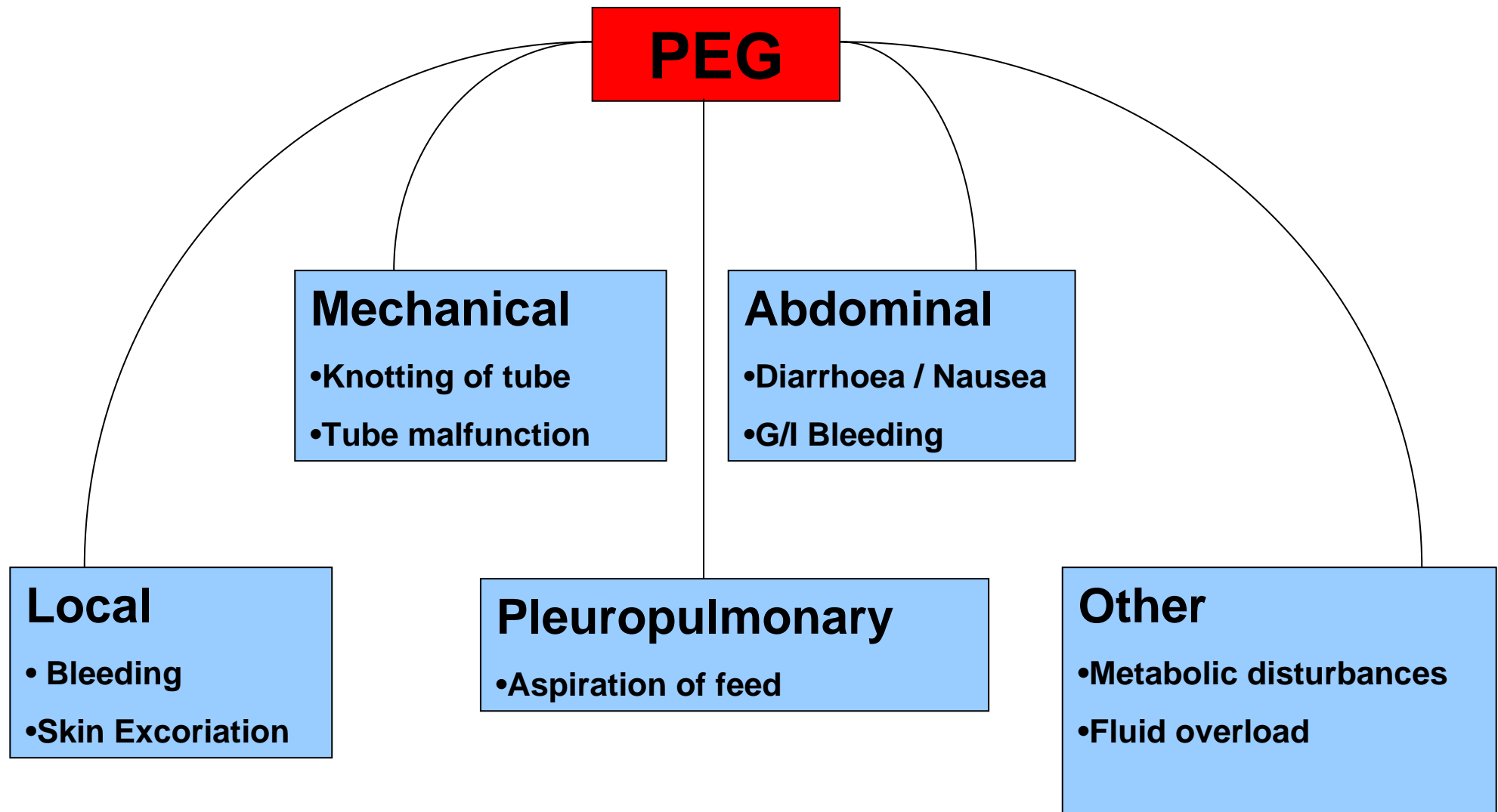
25 - Percutaneous Endoscopic Gastrostomy Feeding (PEG's).

- The process of PEG placement was developed in the 1970's and involves the **surgical insertion of a tube into the stomach through which liquid nutrients are then supplied.**
- It is the **procedure of choice** in virtually all patients with a **functional digestive tract**, who have **impaired swallowing function** or are **unable to take nutrition orally.**
- The development of artificial nutrition has essentially **allowed us to feed patients who cannot eat** and to **continue to feed patients who are dying.**
- The decision to place a PEG tube often **incorrectly focuses primarily on the patient's ability to take food by mouth.**
- **Indiscriminate use of PEG placement has blossomed** into a multi-billion dollar industry with **little thought given to the long and short term implications for vulnerable patients.**

26 - Prevalent PEG Tube myths



27 - Complications of PEG Insertion





28 - PEG – The Research Evidence

Key findings of Research:

- **24 % Mortality at 1 Month.**
- **23.5% Died during PEG insertion / hospitalization.**
- **Median survival 7.5 months.**
- **Pts Age > 60 yrs (Stroke 41%; Neurologic 35%; Cancer 13%).**
- **22% Mortality at 30 days.**
- **50% Mortality at 1 Year.**
- **70% of Pts who survived > 60 days had no improvement.**

Research Studies cited:

- Grant, Rudberg, Brody (1998) USA Study.
- Rabeneck, Wray, Peterson (1996) USA.
- Callahan, Haage (2000) USA

29 - Local Box Hill Study (2004) Melbourne

- Study by my colleague – Associate Professor Graham Schmidt.
- Confirmed findings of the international studies.
- Cohort some 18 patients over 6 month period.
- 12 patients died after PEG placement.
- 4 died within 6 weeks of PEG placement.
- Confirmed that lifespan is not increased by the insertion of a PEG feed.
- PEG placement delays / interrupts the dying process.
- **Ballarat Study** - Pamela Van der Riet et. al.





30 - PEG – Who should get one ?

- The **mechanics of the surgical insertion** are relatively straightforward – Correct **appraisal of the body's ability to assimilate** the feed are complex - Requires detailed consideration, by a **skilled multidisciplinary team**.
- A **PEG referral should not be seen as a choice between life and death**. Instead it is a **medical intervention requiring 'informed consent'**, taking account of the **benefits, as well as, the burdens of treatment**.
- **Appropriate referrals** include **healthy individuals (without multiple organ failure)** where very early in the illness, the **patient develops an inability to eat**.
- Occasionally, a decision for PEG placement is appropriate in the context of a **terminal illness**.
- For example, patients with **motor neurone disease, amyotrophic lateral sclerosis** and patients with a **head or neck tumors, post-Stroke patients** (with a good chance of recovery) and those with **Cerebral Palsy**.
- To provide **direct access for medication otherwise not available to the patient**.



31 - PEG – Who shouldn't get one ?

- Patients with reversible causes of reduced food intake.
- For example, inadequately treated pain, nausea, obstruction, an inability to swallow, poorly fitting dentures, malabsorption and clinical depression.
- Patients in the “terminal phase” of their illness that develop the “anorexia - cachexia syndrome” or “Refeeding Syndrome”.
- End stage Dementia is a common disorder that frequently leads to triad of conditions involving Anorexia, Dysphagia and Weight loss.
- The work by Finucane and others shows that this ‘triad of conditions’ is not addressed by insertion of a PEG.

Peck et. al. (1990) found that 71% of patient's with dementia were restrained.



32 - Summary - Percutaneous Endoscopic Gastrostomy Feeding (PEG's).

- It is a **normal part of the dying process and advanced Dementia** for there to be a gradual reduction, and eventual cessation in oral intake.
- There is now **overwhelming research evidence which demonstrates that most dying patients do not experience hunger, given the physiological process of 'shut-down'**.
- Further the process of **PEG insertion is unlikely to alleviate the symptoms of dehydration such as thirst, headache, nausea, vomiting, and dry mouth.**
- A **comprehensive program of hand-feeding is the proper treatment** in elderly demented patients.
- **No clinical studies suggest that the absence of MH&N during the dying process causes suffering** provided adequate palliative care, including mouth care is provided.
- Recent comprehensive Victorian research indicates that, **family members were under the distinct impression that the non-provision of fluid and nutrition would result in suffering for the dying person.**