National Office for Human Rights and Equality Policy

Consent

hello
my name is...

Marie Tighe

Human Rights

Principles of Consent

Autonomy

- Fundamental principle in ethics
- Being human and worthy of respect
- Persons’ actions and decisions are one’s own and should be respected.
- Persons’ right to control their own life and to decide what happens to their own body – bodily integrity
- Person making informed decisions about the care, support or treatment that they receive.
- Respect a persons’ right to consent/refuse treatment or care.
-

IHREC

Irish Human Rights and Equality Commission

- Promote and protect human rights and equality
- Building a culture of respect
- All public bodies in Ireland have responsibility to promote equality, prevent discrimination and protect the human rights of their employees, customers, service users and everyone affected by their policies and plans

What is consent?

“Consent is the giving of permission or agreement for an intervention, receipt or use of a health and social care service or participation in research following a process of communication about the proposed intervention” (HSE National Consent Policy 2019)

What is consent?

What is consent?

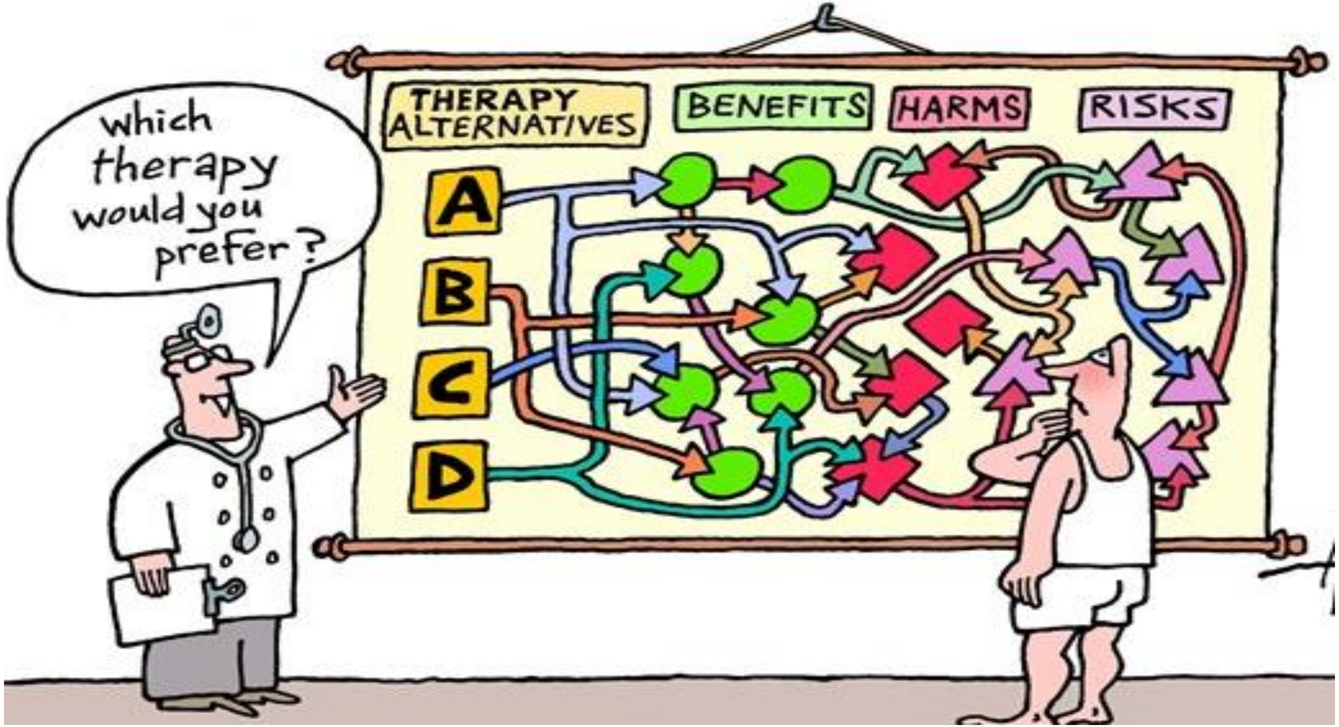
Informed Consent is a **process** of clear communication about choices

Informed Consent → **Informed Choices**

It is not a signature on a form

The consent form is exists to document that the person has been provided with information, has understood the information and has agreed to the particular intervention, receipt or use of a health or social care service or participation in research following a process of communication

Valid and informed consent



What is valid and informed consent?

For consent to be valid and informed, the person must:-

- sufficient information in a manner that the ‘reasonable’ person can understand
- decision made is voluntary - no duress/coercion
- understand they have a choice
- have decision-making capacity

(Presumption of capacity unless the contrary is shown - people don’t need to “prove” they have capacity)

What information?

- Sufficient information – adapted for the person (reasonable person)
- Diagnosis and prognosis including any uncertainties
- Option for treating or managing the condition including the option not to treat
- Purpose of any proposed intervention and what it will involve
- Potential benefits, risks, and the likelihood of success of a proposed intervention as well as that of any available alternative
  - Likelihood intervention will be successful;
  - Risks of doing nothing or taking an alternative approach.
  - If relevant, costs
  - Common, even if minor, side effects or complication
  - Rare but serious outcomes - death, permanent disability...
  - Helpful to put risks in perspective
- Whether proposed investigation or treatment is part of a research project

Summary: Informed Consent

- Explain benefits, harms and risks
- Include all options including doing nothing
- Remain neutral
- Acknowledge uncertainty
- Specify duration
- Be complete
- Avoid subjectivity e.g.. very likely
- Present information in more than one way e.g. 1 in 5 gets this complication and 5 in 6 did not

When should you get consent?

Process of communication

- Continuous process as peoples conditions or interventions may change
- Before any intervention, receipt or use of a health and social care service or participation in research
- Well in advance if possible - affords people time to reflect
- Timeframe - short v long

When should you get consent?

- Need to confirm as people:-
  - Forget/misunderstand
  - may have been given conflicting information or got misinformation
  - may be confused
- Person need clarity if:
  - treatment provided in stages and changes might be needed
  - different professionals provide particular parts of a treatment, e.g. anaesthesia and surgery
  - additional problems arise during an intervention when person may not be in a position to speak

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When should you get consent?

Where the patient declines information

- Should be respected as far as possible
- Give some basic information - major interventions so consent can be obtained. If a person refuses to receive detailed information about their condition, this should be documented.
- The fact that a person might be upset or refuse treatment as a result of receiving information is not a valid reason for withholding information that they need or are entitled to know.

When should you get consent?

Emergency situations

- Life-threatening situation - person lacks capacity or urgency imposes limitations on discussions, necessary treatment may be administered
- **Limited to situations where the treatment is immediately necessary to save the life or preserve the health of the patient.**

When should you not get consent?

- Just before a procedure is about to start
- If a person:-
  - is sedated,
  - in pain
  - is anxious

Who should obtain consent?

- The person providing the health and social care service/intervention.
- May be delegated to another suitably trained and qualified professional with sufficient knowledge
- If different aspects of care are provided by different professional disciplines, each should usually obtain consent for their particular intervention.

How should consent be documented?

- Healthcare record/persons’ record
- Discussions and the person’s agreement and more detailed information if:-
  - the intervention is invasive, complex or involves significant risks;
  - there may be significant consequences for employment, or social or personal life;

How should consent be documented?

- Agreement can be documented by a signature (or mark if unable to write) on a consent form or through documenting in their notes that they have given verbal consent.

- The consent form exists to document that the person has been provided with information, has understood the information and has agreed to the particular intervention, receipt or use of a health or social care service or participation in research following a process of communication

- **Consent form is not proof that an adequate process of communication has occurred or that the consent is valid.**

Who can consent?

- **<u>ALL</u>** people have the right to make decisions and choices about their own lives
- Every adult person is presumed to have the decision-making capacity to decide whether to consent to, or refuse consent unless the contrary is shown.
- A person does not have to prove their capacity to make a decision.

Role of 'Next of Kin'? None

- A false belief persists among staff and the public that consent should be sought from the 'next of kin' if a person can't consent
- *Who is the next of kin anyway?*

Role of Next of Kin

11-14

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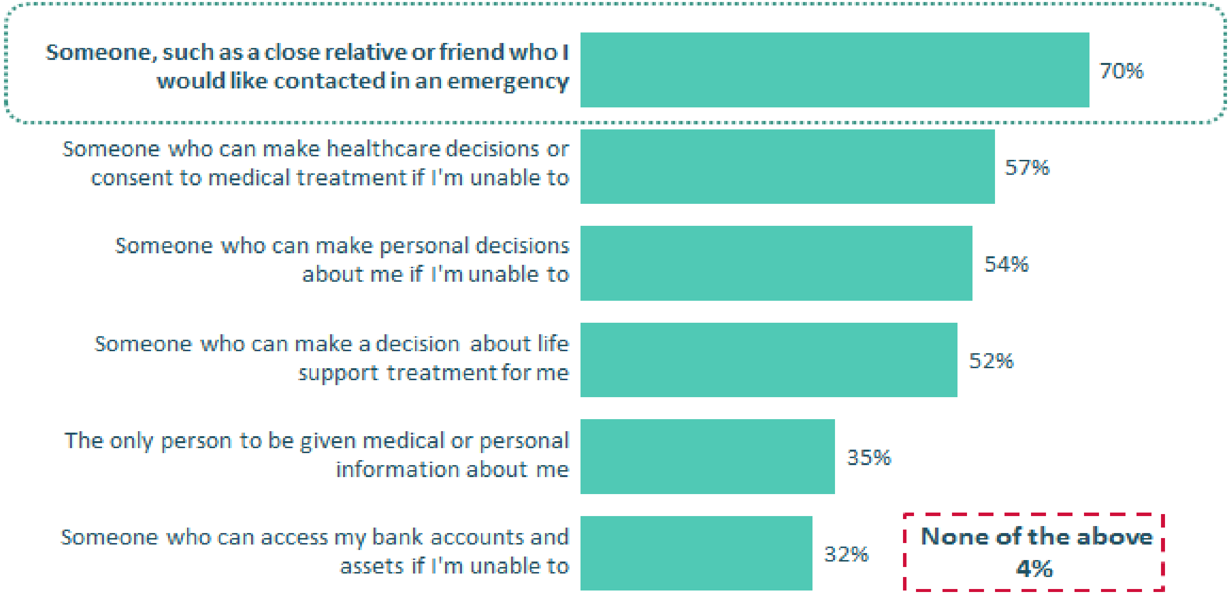
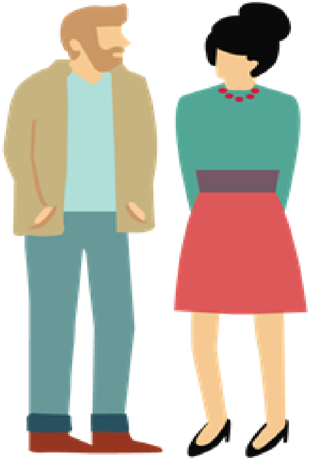
"If you order the chili, I need to know your next of kin."

Which of the following do you feel is the role of your 'Next of Kin'?

(Base: All Adults; n=1,020)





7 in 10 believe that **'Next of Kin'** is somebody to be contacted in an emergency. More than half believe **'Next of Kin'** is associated with making healthcare or personal decisions on their behalf, if they are unable to do some themselves. Only 4% do not associate the role of **'Next of Kin'** with any of the statements.

REDC

(Q.1)

National Consent Policy QPSD-D-026-1. V.1

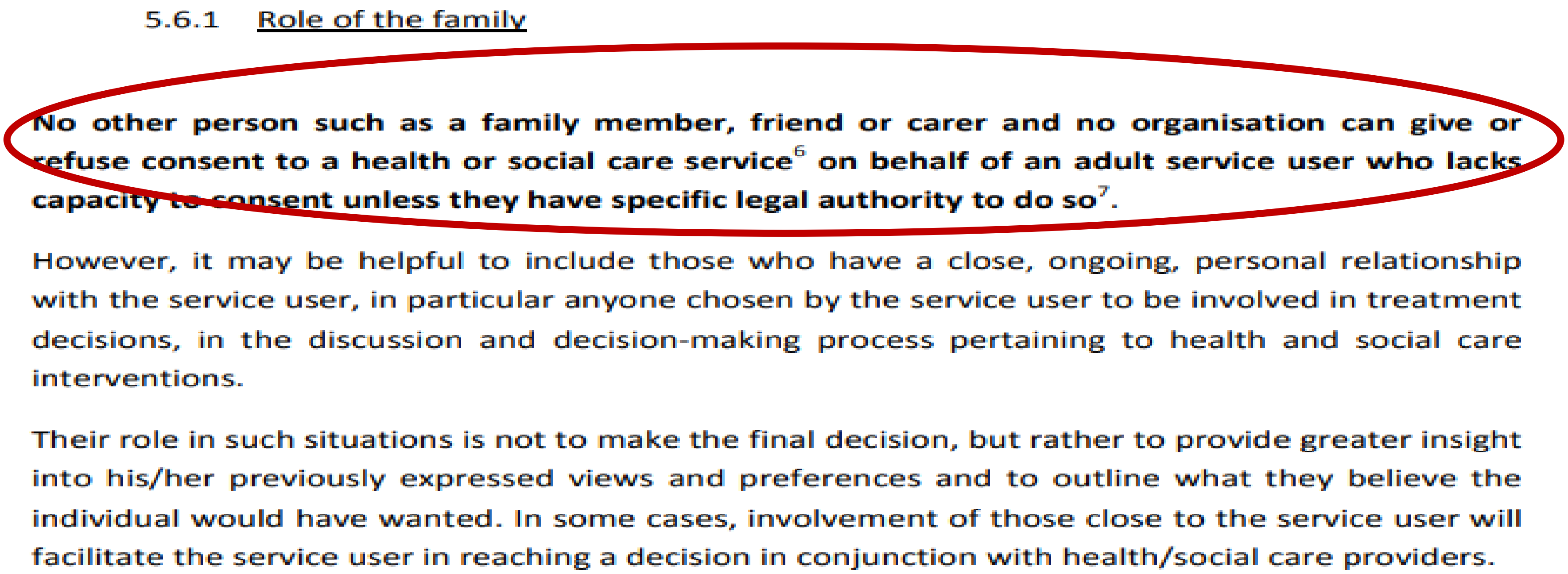
Tús Áite do Shábháilteacht Othar
Patient Safety First

Quality and Patient Safety Directorate

National Consent Policy

This is a controlled document and may be subject to change at any time

Role of ‘Next-of-Kin’ HSE NCP

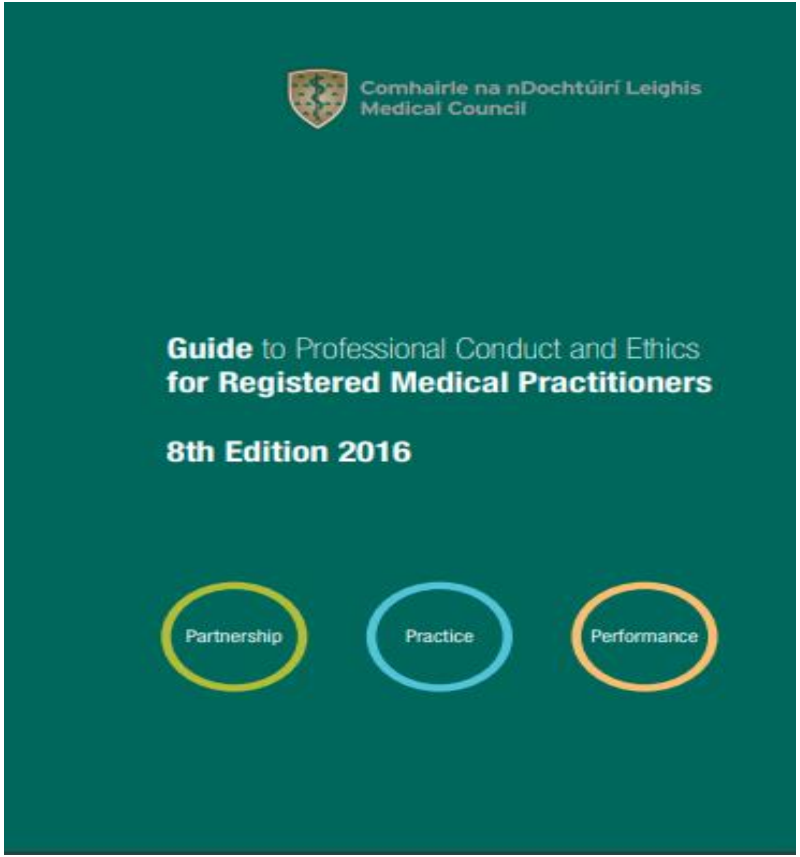


5.6.1 Role of the family

No other person such as a family member, friend or carer and no organisation can give or refuse consent to a health or social care service[6] on behalf of an adult service user who lacks capacity to consent unless they have specific legal authority to do so[7].

However, it may be helpful to include those who have a close, ongoing, personal relationship with the service user, in particular anyone chosen by the service user to be involved in treatment decisions, in the discussion and decision-making process pertaining to health and social care interventions.

Their role in such situations is not to make the final decision, but rather to provide greater insight into his/her previously expressed views and preferences and to outline what they believe the individual would have wanted. In some cases, involvement of those close to the service user will facilitate the service user in reaching a decision in conjunction with health/social care providers.



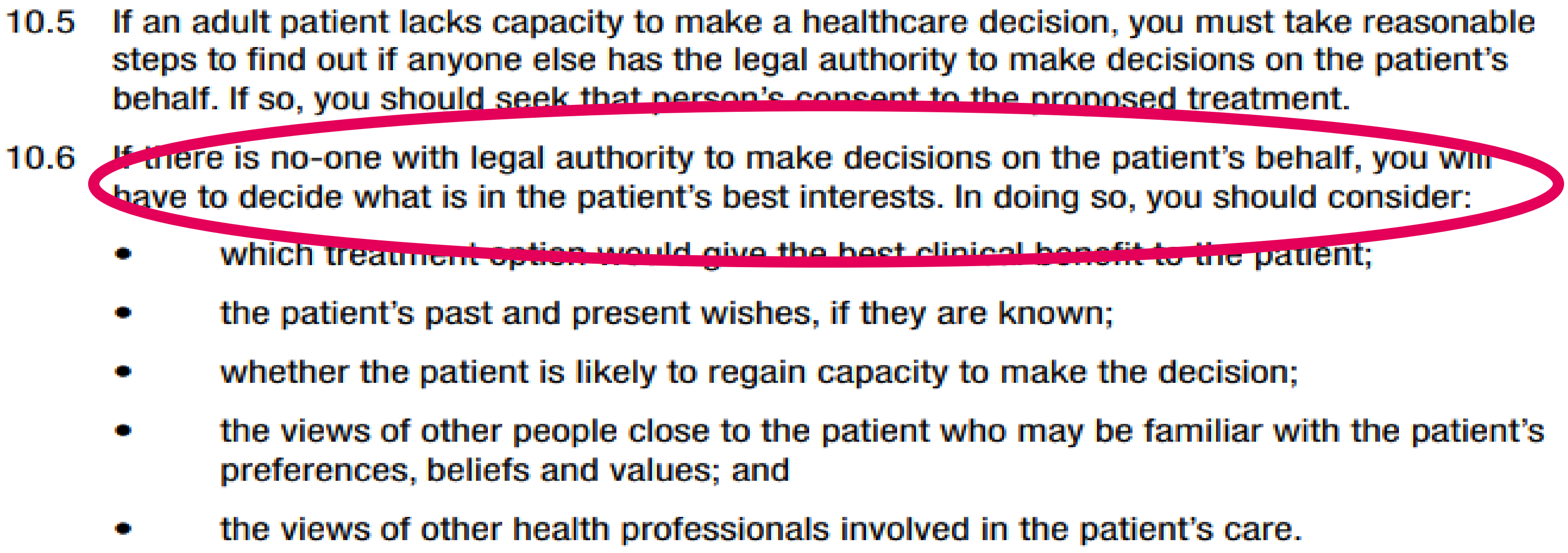
Comhairle na nDochtúirí Leighis
Medical Council

Guide to Professional Conduct and Ethics
for Registered Medical Practitioners

8th Edition 2016

Partnership
Practice
Performance

The Guide to Professional Conduct and Ethics for Registered Medical Practitioners 8th Edition



10.5 If an adult patient lacks capacity to make a healthcare decision, you must take reasonable steps to find out if anyone else has the legal authority to make decisions on the patient's behalf. If so, you should seek that person's consent to the proposed treatment.

10.6 If there is no-one with legal authority to make decisions on the patient's behalf, you will have to decide what is in the patient's best interests. In doing so, you should consider:

- which treatment option would give the best clinical benefit to the patient;
- the patient's past and present wishes, if they are known;
- whether the patient is likely to regain capacity to make the decision;
- the views of other people close to the patient who may be familiar with the patient's preferences, beliefs and values; and
- the views of other health professionals involved in the patient's care.

Question

Who can give consent if the person lacks capacity?

Presumption of capacity

- Starting point - presumption of capacity
    - Every adult person is presumed to have the decision-making capacity to consent/refuse
    - A person does not have to prove their capacity to make a decision.
    - Do not make assumption for any person
    - Making an “unwise” decision is not indicative of lacking capacity to make a decision

(Presumption of capacity is to consent and decision making what the presumption of innocence is to criminal law.)

Supporting the person

- Healthcare workers have a duty to maximise person's their ability to make their own decisions

- Provide information in a way that will best support person to make their own decision, e.g.. right place and time
- Right time and place
- Adequate time and support, including, if necessary, repeating information
  - Use of simple, clear English and avoidance of medical terminology
  - Professional interpreter if needed
  - Supplement verbal information with information leaflets or visual aids
  - Easy read version
- Ask if the person might like to have a relative or friend accompany them
- If appropriate, these should be provided in advance to people (and/or those close to them).
  - For some, it will be easier if the information is given verbally by healthcare workers.

Benefit, Will and Preference

People are all different and want different things

- What matters most to a person
- Quality of life
- Minimising pain
- Getting back to work
- Reducing risk of future illness/injury
- Length of life

Concerns

- Complications
- Loss of independence
- Likelihood of success

Will and preferences

- Ask the person
- Ask those close to the person
- What were their previously expressed wishes and preferences
- Healthcare record/any other record

Decision-making requirements

A person lacks the capacity to provide or refuse consent to an intervention if he or she is unable

- to understand the information relevant to the decision,
  - Does the person understand the information relevant to the decision, including the risks of refusing?
  - General understanding of the most important points - person doesn’t have to become an expert
- to retain that information long enough to make a voluntary choice, and
  - it’s not a memory test – the information only needs to be retained for long enough to make a decision.
- to use or weigh that information as part of the process of making the decision, or
- to communicate his or her decision (whether by talking, writing, using sign language, assistive technology, or any other means)

Who has legal authority?

- In practice, almost nobody!!
- Wards of Court - the court/committee
  - In the case of a dispute with the committee of the ward that cannot be resolved locally, the matter should be referred to the Registrar of the Wards of Court.
- (Enduring Power of Attorney made under current law does not include a healthcare decision).

Will and preference – when a person lacks decision-making capacity

- National Advocacy service use four internationally recognised approaches to ascertain a persons’ will and preference
  - Person centredness
  - Witness observer
  - Rights based approach
  - Ordinary Life principles (based on the 8 domains of quality of life)

PERSON CENTREDNESS

- Files/records/healthcare files/AHD
- Speak to those who know person well (to inform, never to decide).
- Values/Beliefs/Preferences/attitudes?
- Views on other interventions/services?
- Past behaviours /convictions?
- Cultural, religious, ethnic factors?
- Consider conflicts of interest

WITNESS OBSERVER

- Impact of intervention/service (allow reasonable accommodation - time/numbing gel/any support)
- Observe responses of person (Pushing away or walking away? Withdrawing? Content? Distressed?)
- Body language, facial expressions, vocalisations, gestures?

RIGHTS BASED APPROACH

Respecting the person’s human rights:

- Right to Life
- Right to bodily integrity
- FREDA principles
- HSE Consent Policy - no ‘next of kin’ decision making/assumed authority

ORDINARY LIFE PRINCIPLES

8 domains of quality of life

- Well-being: Material benefits and risks
- Medical considerations: GP/ other healthcare professionals
- Quality of Life: impact? Social life/ Community Access
- Relationships with others?

What if those close to a person disagree with decision?

- Explore why they disagree
- Carefully consider their views
  - They are closer to and know the person best
  - They may have a better insight in likely will and preferences
  - Nobody wants those close to be the person to be upset
- Seek to allay concerns
- Consider involving an independent advocate
- Last resort - the court

Why improve the process?

- Consent - treated as a formality with focus on getting the form signed
- Time challenges
- Even after process people have limited understanding of:-
    - benefits, risks and harms of the proposed treatment
    - Possibility of poor outcomes
    - Option of refusing and saying no

Benefits of a quality process

- Supports people to make informed decisions
- Strengthens the therapeutic relationship
- Improves follow up and aftercare
- Engages people, their families and/or those close to them
- Increase patient satisfaction
- Averts cancellations of interventions
- Helps prevent litigation

No man is good enough to govern another man without the other's consent.

Abraham Lincoln