Ethical Issues in Stroke Care: Working with Substitute Decision Makers

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Event objectives:

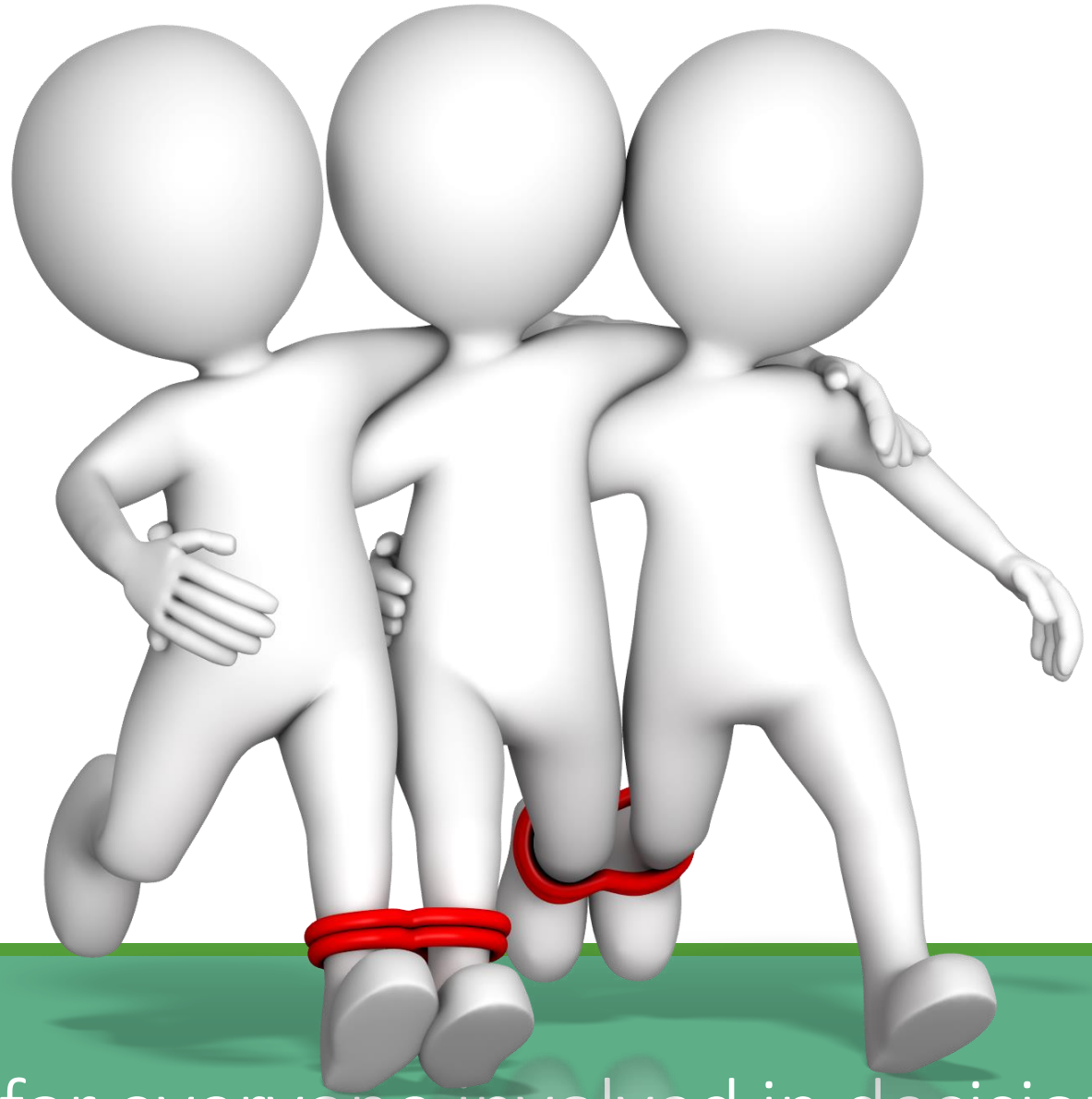
Identifying ethical issues

Clarify consent, capacity and substitute decision-making

When do you turn to substitute decision maker for care decisions

How does cognitive impairment and aphasia impact consent and capacity?

Navigating ethical dilemmas surrounding feeding tube and issues at discharge



Role clarity for everyone involved in decision-making can go a long way

What decisions require consent under the Health Care Consent Act?

TREATMENT, PLACEMENT, PERSONAL ASSISTIVE SERVICES

Treatment

- done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose

Admission to LTC

- Long-term Care

Personal Assistance Services

- means assistance with hygiene, washing, dressing, grooming, eating, drinking, elimination, ambulation, positioning or any other routine activity of living

No Consent needed for …

Emergencies

Leaving the hospital

Going to retirement home

Going home

Taking alternative medicines

When can a client/patient make decisions about themselves?

ALL PATIENT/CLIENTS ARE PRESUMED CAPABLE

Capacity = Ability to understand the situation & ability to appreciate the consequences of making a decision about the situation

A PERSON CAN BE CAPABLE AND HAVE COGNITIVE DEFICITS, CHALLENGES SPEAKING, MENTAL ILLNESS, OR PSYCHIATRIC ISSUES, AND BE CAPABLE

MUST HAVE THE ABOVE TO BE CAPABLE

Who and how does one determine capacity for decision-making?

PRACTITIONER PROPOSING THE PLAN EVALUATES CAPACITY.

How do you evaluate capacity when there is aphasia, communication challenges or cognition issues?

CAPACITY = ABILITY TO UNDERSTAND THE SITUATION & ABILITY TO APPRECIATE THE CONSEQUENCES OF MAKING A DECISION ABOUT THE SITUATION

COMMUNICATION TOOL ARE KEY & PRIOR EXPRESSED WISHES

Can a family member make decisions for a patient when the patient/client is capable?

NO – NOT VALID CONSENT

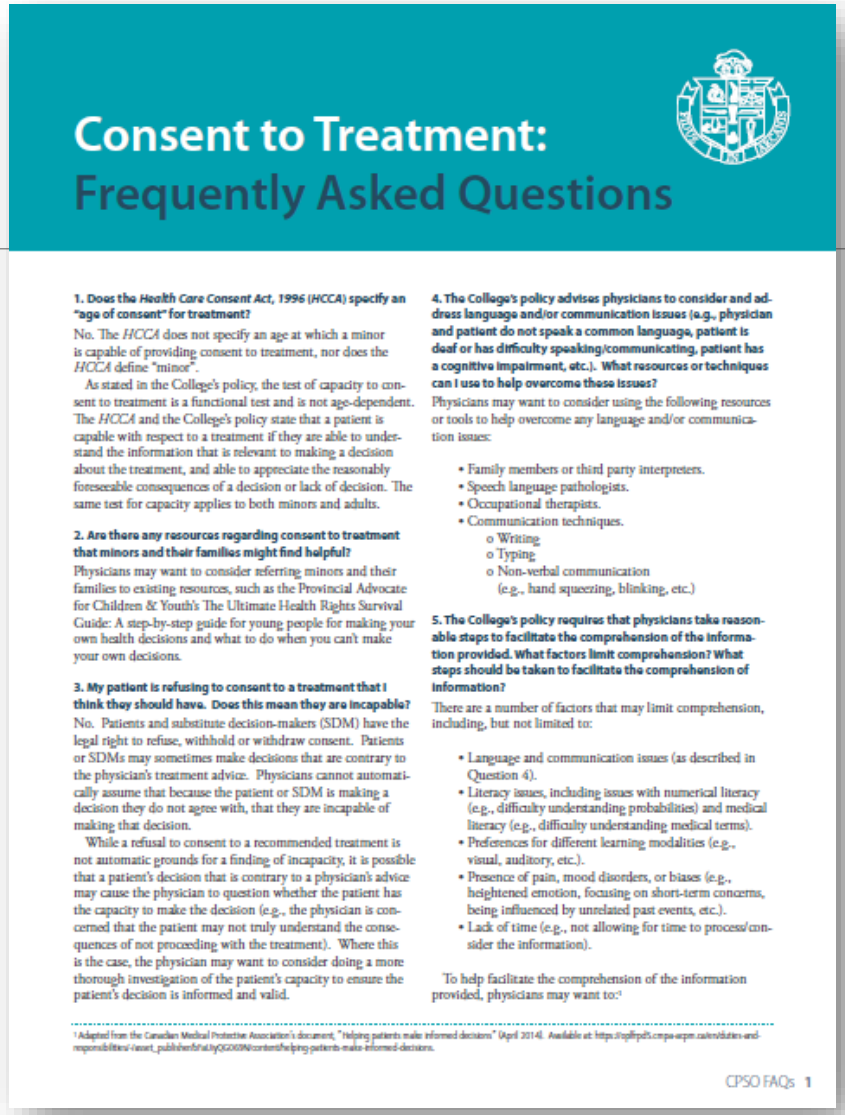
“Just talk to my daughter, please”

DEFERRING TO A FAMILY MEMBER IS COMMON BUT IS THE CONSENT VALID?

A patient cannot defer consent

HCP are required to obtain consent from the patient if capable for the consent to be valid

A HCP can encourage patients to speak to family or daughter but the patient must be the one who hears about and assesses the risk and benefits in order for the decision to be informed and valid consent obtained



Consent to Treatment: Frequently Asked Questions

1. Does the *Health Care Consent Act, 1996* (*HCCA*) specify an "age of consent" for treatment?

No. The *HCCA* does not specify an age at which a minor is capable of providing consent to treatment, nor does the *HCCA* define "minor".

As stated in the College's policy, the test of capacity to consent to treatment is a functional test and is not age-dependent. The *HCCA* and the College's policy state that a patient is capable with respect to a treatment if they are able to understand the information that is relevant to making a decision about the treatment, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision. The same test for capacity applies to both minors and adults.

2. Are there any resources regarding consent to treatment that minors and their families might find helpful?

Physicians may want to consider referring minors and their families to existing resources, such as the Provincial Advocate for Children & Youth's The Ultimate Health Rights Survival Guide: A step-by-step guide for young people for making your own health decisions and what to do when you can't make your own decisions.

3. My patient is refusing to consent to a treatment that I think they should have. Does this mean they are incapable?

No. Patients and substitute decision-makers (SDM) have the legal right to refuse, withhold or withdraw consent. Patients or SDMs may sometimes make decisions that are contrary to the physician's treatment advice. Physicians cannot automatically assume that because the patient or SDM is making a decision they do not agree with, that they are incapable of making that decision.

While a refusal to consent to a recommended treatment is not automatic grounds for a finding of incapacity, it is possible that a patient's decision that is contrary to a physician's advice may cause the physician to question whether the patient has the capacity to make the decision (e.g., the physician is concerned that the patient may not truly understand the consequences of not proceeding with the treatment). Where this is the case, the physician may want to consider doing a more thorough investigation of the patient's capacity to ensure the patient's decision is informed and valid.

4. The College's policy advises physicians to consider and address language and/or communication issues (e.g., physician and patient do not speak a common language, patient is deaf or has difficulty speaking/communicating, patient has a cognitive impairment, etc.). What resources or techniques can I use to help overcome these issues?

Physicians may want to consider using the following resources or tools to help overcome any language and/or communication issues:

- Family members or third party interpreters.
- Speech language pathologists.
- Occupational therapists.
- Communication techniques.
  - Writing
  - Typing
  - Non-verbal communication (e.g., hand squeezing, blinking, etc.)

5. The College's policy requires that physicians take reasonable steps to facilitate the comprehension of the information provided. What factors limit comprehension? What steps should be taken to facilitate the comprehension of information?

There are a number of factors that may limit comprehension, including, but not limited to:

- Language and communication issues (as described in Question 4).
- Literacy issues, including issues with numerical literacy (e.g., difficulty understanding probabilities) and medical literacy (e.g., difficulty understanding medical terms).
- Preferences for different learning modalities (e.g., visual, auditory, etc.).
- Presence of pain, mood disorders, or biases (e.g., heightened emotion, focusing on short-term concerns, being influenced by unrelated past events, etc.).
- Lack of time (e.g., not allowing for time to process/consider the information).

To help facilitate the comprehension of the information provided, physicians may want to:[1]

[1] Adapted from the Canadian Medical Protective Association's document, "Helping patients make informed decisions" (April 2014). Available at: https://oplfrp05.cmpa-acpm.ca/en/duties-and-responsibilities/-/asset_publisher/fsFaUhyQGO0N/content/helping-patients-make-informed-decisions.

Can a patient/client refuse the practitioner's treatment plan?

Any time

It is assault to treat without consent

If you don't give consent then the patient/client will not get treatment (unless its an emergency)

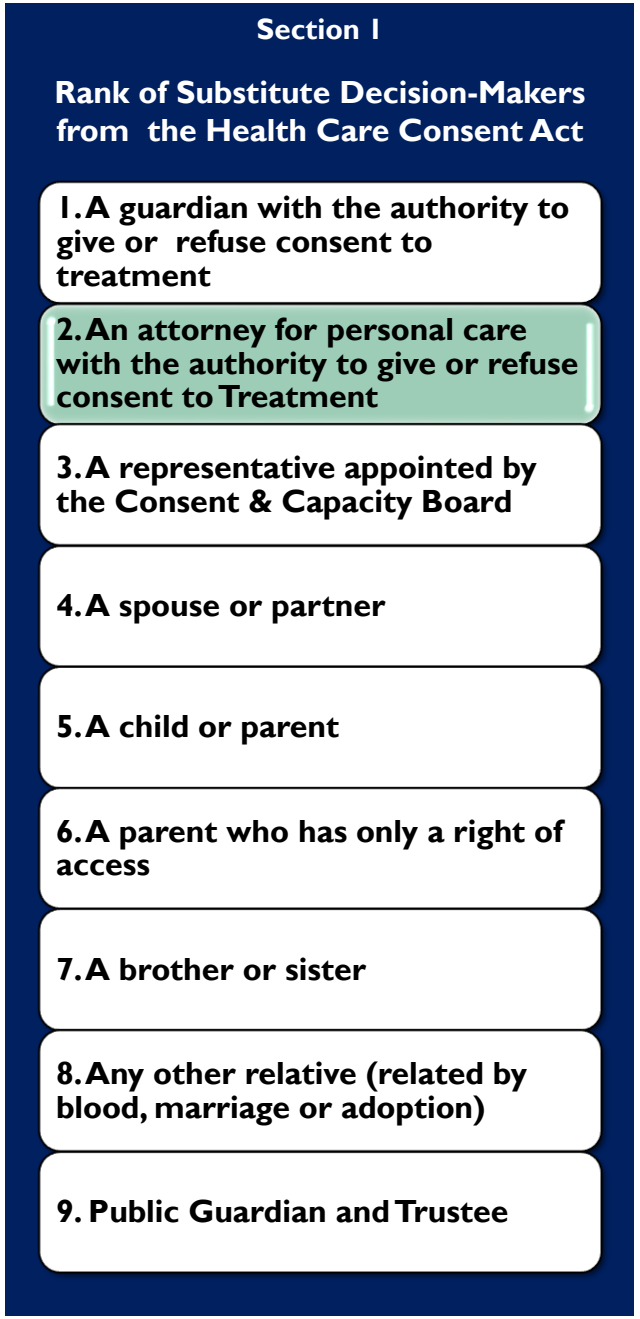
When does a SDM get involved in decision-making?

ONLY WHEN THE CLIENT/PATIENT IS INCAPABLE OF MAKING A DECISION BASED ON THEIR ABILITY TO UNDERSTAND AND APPRECIATE

So what if the patient/client is not capable to consent?

WHAT THEN – WHO DO YOU TURN TOO?

Substitute Decision-maker (SDM)



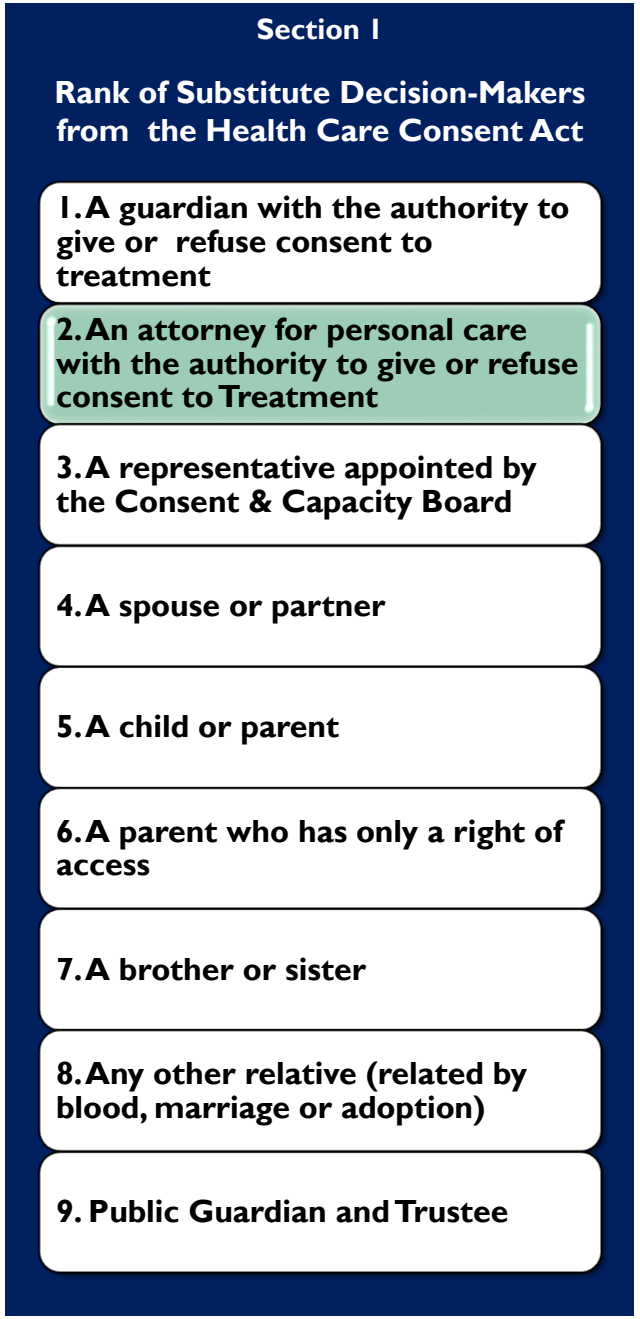
Before we turn to this hierarchy …

DOES THE PATIENT/CLIENT GET A CHANCE TO CHALLENGE?

Patient/client must be told they are incapable

THEY CAN CHALLENGE THROUGH A ***FORM A*** AT THE CONSENT & CAPACITY BOARD

Substitute Decision-maker (SDM)



How often does a person have to be assessed to be determined to not have capacity?

EACH TIME THERE IS A NEW DECISION

CAPACITY IS MEASURE FOR EACH DECISIONS

INCAPACITY IS NOT GLOBAL

Can a patient have capacity for some decisions and not for other decisions?

YES – AND THERE IS NO REQUIREMENT TO BE CAPABLE ALL THE TIME

If there are two equal standing SDMs e.g. siblings and they disagree on the plan of care , whose direction do you take?

PGT

What if you can never reach the SDM?

GO DOWN THE HIERARCHY

SDM MUST BE WILLING, CAPABLE & AVAILABLE

Who do you turn to if both patient and partner is not capable?

NEXT PERSON ON THE HIERARCHY

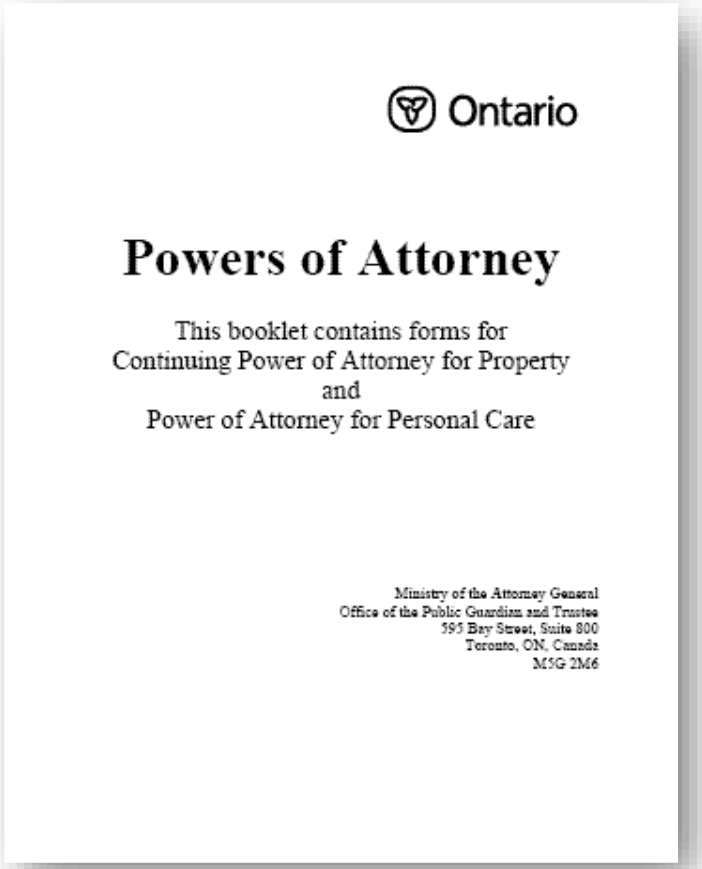
THE SDM CANNOT APPEAL THIS DECISION

Can patients/clients choose their own SDM?

YES – THIS PERSON IS CALLED A POA

HIGHLY VALUABLE WHEN PATIENT/CLIENT DOES NOT TRUST ANYONE ON THE HIERARCHY TO FOLLOW HIS/HER WISHES WHEN THEY ARE INCAPABLE

Complete POA Kit - Appoint someone


Ontario

Powers of Attorney

This booklet contains forms for
Continuing Power of Attorney for Property
and
Power of Attorney for Personal Care

Ministry of the Attorney General
Office of the Public Guardian and Trustee
595 Bay Street, Suite 800
Toronto, ON, Canada
M5G 2M6

You can appoint someone specific

- POA only makes decisions *on your behalf* when you become incapable – not before
- Can be appointed anytime
- And be changed anytime
- Do not need a lawyer

Patients/clients should choose someone who they trust will follow their wishes when they become incapable

“I know my daughter won’t follow my wishes – she told me”

WHAT NOW? THIS A SINGULARLY IMPORTANT ROLE FOR POA KIT

Can a friend be an SDM?

CAN BE APPOINTED A REPRESENTATIVE USING A *FORM C* AT THE CONSENT & CAPACITY BOARD

Can an SDM override the wishes of an patient at EOL?

IF THEY NO LONGER APPLY TO THE CIRCUMSTANCES

USUALLY NOT

Outline the role of SDM when you first meet them and set yourself up for success

Role of SDM

Prior expressed wishes of patient

Best interests of patient

Must be willing, capable and available

Only active when there is a decision requiring consent

Only active when patient is incapable

What do you do when the team has a difference of opinion?

DO YOU KNOW THE WISHES, VALUES, BELIEFS OF THE CLIENT/PATIENT

What should happen when the family and patient disagree?

ROLE CLARITY IS KEY – THE PATIENT/CLIENT WISHES, BELIEF AND VALUES GUIDE DECISION-MAKING

How do you determine best interest of the client?

BEST INTERESTS ARE DETERMINED BY CONSIDERING THE VALUES & BELIEFS OF THE PATIENT/CLIENT AND THOSE DECISIONS THAT PROMOTE BENEFITS AND REDUCE DECLINE FOR THE PATIENT/CLIENT

What is required for consent regarding a feeding tube?

INFORMED CONSENT FROM PATIENT/CLIENT

PROPOSAL BY PRACTITIONER – INDICATED

CONSENT

What do you do when then team is struggling with the SDM's decision

CLARIFY WHO PROPOSED TREATMENT PLAN

IS IT IN LINE WITH CLIENTS/PATIENTS WISHES

IS IT IN BEST INTERESTS

Can the SDM name someone else in their absence?

NO – YOU HAVE TO GO DOWN THE HIERARCHY

AND THE PERSON ASKING NEEDS TO BE TOLD THIS

What do you do when SDM is not following incapable person wishes?

CONSENT & CAPACITY BOARD

What happened when there is no SDM?

HCP WILL GO TO PUBLIC GUARDIAN & TRUSTEE

Going home …

ISSUES AT DISCHARGE

No Consent needed for …

Emergencies

Leaving the hospital

Going to retirement home

Going home

Taking alternative medicines

Can someone be held in hospital under the Health Care Consent Act against their will when the discharging MRP feels they are not capable of managing on their own in the community?

NO

MHA – FORM 1 – BUT THERE MUST BE PSYCHIATRIC ISSUES

How do teams manage when there is risk associated with discharging patients and the patient is capable?

CLARIFY THE RISKS – IS THE PATIENT/CLIENT ACCEPTING OF THESE RISKS

SET UP SUPPORTS & MAKE REFERRALS

What to do when a patient/client has impaired cognition but is still capable to make a poor decision to discharge home alone

OFFER AVAILABLE SUPPORT AND OUTLINE POTENTIAL RISKS TO SUPPORT INFORMED DECISION-MAKING

Is there such a thing as “to high a risk to go home?”

WHEN THE TEAM HAS WORRIES ABOUT WHAT MIGHT HAPPENS WHEN AT HOME

What do you do when clients make risky decisions?

MAKE SURE THEY ARE INFORMED OF THE RISKED THEY ARE DECIDING ABOUT

QUESTIONS

Case Study

Patient/client asking to go home

Team thinks it is too risky

Family agrees with team

The patient/client is attempting to leave on his own and falling

What should we do?