NHS Education for Scotland

Think Capacity Think Consent

Supporting application of the Adults with Incapacity (Scotland) Act (2000) in Acute General Hospitals

Learning Resource

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Contents

Introduction

Assessment of capacity to consent to treatment is an important legal and ethical issue for staff working in acute general hospitals. It is estimated that between 30% and 52% of people admitted to hospital will lack capacity to consent to treatment.

Capacity to consent **must always be** assessed and incapacity **should never be presumed** because a person has a particular health condition or disability, for example mental health problems, learning disabilities, or dementia.

Without proper legal authorisation the person's right to make decisions about their care can be violated. The Adults with Incapacity (Scotland) Act 2000 (AWI)[1] places an obligation on all staff to understand legislation and apply it appropriately.

This learning resource provides essential information about the application of Part 5 of the Adults with Incapacity (Scotland) Act 2000 (AWI) to ensure staff in acute general hospital settings safeguard the rights of people who lack capacity to consent to treatment.

This learning resource can be studied independently, in a group, or in a facilitated learning session. As well as providing you with key learning, scenarios are used to help encourage exploration and reflection about real practice issues.

Learning Outcomes

On completion of this learning resource you should understand:

1. The powers and provisions of the Adults with Incapacity (Scotland) Act 2000 (AWI) in relation to capacity and consent to treatment.
2. The assessment of capacity and incapacity to consent to treatment.
3. The application of the principles and powers of the AWI Act to your practice.

1. Scottish Executive (2000) *The Adults with Incapacity (Scotland) Act.* Edinburgh: The Scottish Executive [online] Available: http://www.scotland.gov.uk/Topics/Justice/law/awi

Consent to medical treatment while in hospital

In this section we discuss capacity in relation to consent to medical treatment.

Medical treatment is defined as any procedure or treatment designed to safeguard physical or mental health. Therefore it includes fundamental aspects of care such as nutrition and hygiene as well as specific treatments for illnesses or conditions.

Providing treatment against the wishes of a patient capable of consenting to treatment violates the principle of patient autonomy and can constitute assault. Autonomy requires the capacity to think and make decisions consistent with one's own values and the ability to act freely without undue influence from others.

People have a fundamental right to determine what happens to their own bodies, and healthcare professionals must respect that right. Therefore people must give valid consent to all forms of healthcare whether this is personal care or major surgery.

This right to self-determination in a capable adult extends to refusing to undergo any medical intervention, even where this may result in harm or even death.

In an emergency situation, healthcare professionals may provide treatment to patients without consent, provided that the treatment is necessary to preserve life or to prevent a serious deterioration in their condition. Accurate and detailed recording of both the decision and the decision-making process is essential.

How the law in Scotland helps to safeguard people's rights and choices

The law in Scotland presumes all adults 16 years and older have sufficient capacity to decide on their own medical treatment. This presumption of capacity can only be overturned on evidence of impaired capacity, even where the person has a diagnosis that may affect his or her ability to make decisions, for example dementia.

In Scotland the main piece of legislation used to protect the rights of a person who lacks capacity to consent to treatment is **Part 5 of the Adults with Incapacity (Scotland) Act (2000)**.

The Adults with Incapacity (Scotland) Act (2000); (AWI), created a legal framework for making decisions on behalf of a person who does not have the capacity to make decisions. It covers the person's welfare, property, financial affairs and medical treatment. It also enables a person to make their own arrangements about how their affairs should be managed in the future if they lose the capacity to make decisions.

A significant feature of the Act is the introduction of **proxy decision makers** which we will describe in more detail later in the learning resource. Prior to this legislation, under common law, no other person could consent to treatment on behalf of another person.

The Mental Health (Care and Treatment) (Scotland) Act (2003)[2], Adult Support and Protection (Scotland) Act (2007)[3] and the Adults with Incapacity (Scotland) Act (2000) are often referred to as a suite of adult protection legislation.

All set out clear statements of Principles that inform the ethical basis for the provisions of the legislation and the values underpinning it. All three Acts share many of the same principles described in **Appendix 1**, and place a duty on the person or bodies intervening to have regard for the principles which may be the subject of judicial review. These are underpinned and supported by the Human Rights Act (1998) and the Equality Act (2010)[4].

2. Scottish Executive (2003) *Mental Health (Care and Treatment) (Scotland) Act*. Edinburgh: The Scottish Executive [online]. Available: http://www.legislation.gov.uk/asp/2003/13/contents
3. Scottish Government (2007) *The Adult Support and Protection (Scotland) Act.* Edinburgh: The Scottish Government [online] Available: http://www.scotland.gov.uk/Topics/Health/care/adult-care-and-support/legislation
4. Scottish Government (2010) Equality Act. Edinburgh: The Scottish Government: [online] Available: http://www.legislation.gov.uk/ukpga/2010/15/contents

The Principles of the Adults with Incapacity (Scotland) Act (2000)

Any intervention under the Act must take account of the principles and must be followed in any action taken. If not, the action may be subject to legal challenge. The principles are as follows:

- Any action taken on behalf of the person **must benefit** the person.
- Any action must be the **least restrictive option** that will achieve the desired effect.
- Before making a decision on behalf of a person, account should be taken of the person's **past and present views and preferences**.
- Account should be taken of the **views of specific persons** such as guardian, attorney, relatives and any other person appearing to have an interest in the person.
- Anyone acting under the act must **encourage the adult to develop and exercise as much skill as possible** in making decisions or taking actions. All steps must be taken to enhance the person's decision making ability.

What is Capacity and Incapacity?

'Capacity' means the ability to use and understand information to make a decision. The person should be given appropriate information provided in a way that they can understand and can make a decision based on this information. Capacity in relation to consent to treatment means people are capable of understanding the nature, implications and consequences of their decisions. A person is considered to have capacity to consent to treatment if they:

- Understand in simple language what the treatment is, its purpose and nature and why it is being proposed.
- Understand its principal benefits, risks and alternatives and be able to make a choice.
- Have a general understanding of what the consequences will be of not receiving the proposed treatment.
- Can retain the information long enough to use it to weigh up the possible outcomes in order to arrive at a decision.
- Can communicate that decision to others.
- Can hold this decision consistently. This includes occasions when a person has difficultly in remembering a decision but, given the same information at another time, they make a consistent decision. This makes their decision valid.

The AWI Act refers to 'Incapacity' rather than 'capacity' and defines **incapacity** as when a person is incapable of:

a. Acting
b. Making decisions
c. Communicating decisions
d. Understanding decisions
e. Retaining the memory of decisions

Factors that may influence capacity

We also need to consider the many factors that may influence capacity both internal and external to the person such as environment, previous hospital experience, quality and form of information provided, communication and co-existent health problems.

There are multiple factors that may potentially affect and compromise people's capacity to make decisions. These include:

- Personal, physical, psychosocial and situational demands placed on the person.
- The resources and supports available.
- The impact on the person's capacity to make decisions if they are suffering pain or discomfort or taking medication that causes drowsiness.
- Conditions that can affect decision making capacity and these include infections such as pneumonia, urinary tract infection or influenza, delirium, endocrine disorders, cardiovascular disease and chronic pain.

Relationships between people may have a significant impact on decisions made and, therefore, may influence the capacity of someone to make a decision. **For example**, in a relationship where the person is at risk or feels threatened by another person, they may be put under undue pressure to consent or refuse treatment rather than making an autonomous decision. If you suspect that is the case you **must** follow local adult protection procedures, in line with the Adult Support and Protection (Scotland) Act (2007).

Equality and diversity issues, such as someone's ethnic background or disability also needs to be a major consideration in capacity assessment to eliminate the risk of misinterpreting indicators of cultural difference as incapacity and reduced cognitive function. This will require sensitivity to the person's specific cultural needs which may include for example, the use of interpreters or referral for specialist assessment.

It is essential that these factors are considered and all practical steps are taken to enable the person to make the decision themselves. A central component in this is communication and the provision of information in a way that is easily understood by the person as well as maximising residual capacity which is a principle of the Act.

Maximising residual capacity is a statutory duty on any proxy decision maker and is the responsibility of health professionals when there is no proxy decision maker. This involves doing everything possible to encourage, support and enable the person to use their existing skills and develop new ones when capacity is fluctuating or limited. This includes establishing the person's long held values and beliefs as well as their consistency in the decision, when the person has memory impairment. A key factor in achieving this is the relationship between the person and the professional(s) involved in their care and their skills in communication.

The Scottish Government in 2008 produced a useful guide for health and social care staff called *Communication and Assessing Capacity* to support this activity.

The guide makes it clear that the challenge is to find ways to help the person to understand what decision or decisions need to be made and why.

It is available at: http://www.scotland.gov.uk/Resource/Doc/210958/0055759.pdf

Scenario 1

Edith's story below reflects some of the issues that can arise in clinical practice. Take some time to read her story and consider the question posed.

Edith is a 78 year old lady who remains active and enjoys bridge and bowling, despite experiencing arthritic pain in her hips over the past 3 years. She has a diagnosis of dementia but remains positive and feels she has a good quality of life because of her community and family support. Her GP has referred her for assessment and the outcome is that a hip replacement is indicated. However, the orthopaedic consultant is reluctant to perform the surgery. He is concerned that Edith may not retain the information relating to the post operative regime because of her dementia. This could hinder her recovery and risk further complications such as deep vein thrombosis (DVT).

How do you think the Act can be used to aid decision making in this situation?

Record your answer here ▷

Please refer to Appendix 4 for suggested discussion points. ▷

Proxy decision makers under the Adults with Incapacity (Scotland) Act (2000)

Power of Attorney

'Power of Attorney' is the name given to a person or persons granted the authority to make decisions on behalf of a person who becomes incapable of making decisions on their own. A Power of Attorney is taken out in the same way a person creates a will, by providing a statement in writing, usually with legal help. The document must include a certificate from a solicitor or medical practitioner who has interviewed the person granting the power immediately before the document was signed. This certificate confirms that, in the solicitor or medical practitioner's opinion, the granter is capable of making the decision about Power of Attorney, knows and understands what they are doing and, importantly, is free from duress or pressure in making that decision.

It is obviously important that a person gives Power of Attorney to someone they trust, to make decisions when they are no longer capable of making them. We can support people by ensuring they have information about the different powers within the Act to empower and enable them to make decisions and draw up advanced plans.

The legal terms relating to Power of Attorney are:

- **Granter**, the person giving permission to someone else
- **Attorney** (also known as **proxy**), the person who is given the powers

There are two types of Power of Attorney: **Continuing** and **Welfare** Attorneys.

Continuing Attorney

A person with Continuing Powers of Attorney can only manage the **finances and property** of another person and their powers can start immediately after the agreement is signed.

The person giving permission (the granter) may not want this to happen and can specify that the powers should start only when they have lost capacity to manage their own financial affairs. For example, when continuing Power of Attorney is in place, the Attorney would have access to the person's finances and could arrange to do things like to pay household bills.

Welfare Attorney

Welfare Attorneys have power over the person's **personal welfare**. These are things that affect the person's physical and emotional well-being, for example, physical and mental health and protection from abuse and harm (other than financial harm). Powers can include choice of medical care and treatment, choice of diet, personal care, choice of clothing, meaningful social contact with friends, families or communities, and even where the person lives.

Welfare Attorneys can only start making decisions on behalf of the person, once the person has been assessed and it is agreed they no longer have capacity.

All Continuing and Welfare Powers of Attorney must be registered with the Public Guardian. In return, the Public Guardian issues the Welfare Attorney with a Certificate of Registration. The office of the Public Guardian was created by the AWI Act and anyone can contact them for information: **www.publicguardian-scotland.gov.uk**

Intervention Orders

Intervention orders give permission for one-off decisions which the person does not have the capacity to make. The decision may be to do with property, finance or personal welfare. For example, when dealing with income tax or selling a property the person making an application to the court for the order would **not** have to have power of attorney or guardianship. The person would have to have an interest or concern about the person in question. The local authority in the area the person lives may make an application in certain circumstances. A welfare intervention order may be relevant when a person is assessed as not being able to consent to a complex medical treatment, although they can still make most other decisions.

Guardianship Order

Guardianship is different to Power of Attorney in that it can only be applied for when the person is assessed as not having capacity to make decisions. It can cover

property and financial matters or personal welfare, including health, or a combination of all of these. Anyone with an interest in the person may apply to the courts for guardianship e.g. a family member or the local authority. The guardian can then make decisions on behalf of the person in the same way as the Attorney.

The decisions the Attorney or Guardian can make will be specified in the order granted and it should not be presumed that they have the power to make all decisions regarding the care of the person.

Other key elements of the AWI Act that may be relevant to you in your practice are described at **Appendix 2**.

Part 5 of the Adults with Incapacity Act - General Authority to Treat

Part 5 of the AWI Act was implemented in July 2002 and amended with effect from 2005. This amendment extended the authority to treat beyond medical practitioners to include dentists, nurses and ophthalmic opticians with the relevant qualifications experience and competence.

This is *restricted* in that the health professional can only authorise treatment in their own speciality for example a nurse can only authorise nursing interventions. The practitioner is allowed to share the authority to treat with others involved in the person's care and treatment. This may be done by issuing instructions to others; for example, a doctor may prescribe medicines to be administered by nurses.

Section 47 grants a practitioner the general authority to give medical treatment to an adult who lacks capacity to **give or refuse** consent. The lack of capacity must arise from the adult having a mental disorder or an inability to communicate which affects their ability to make decisions about the treatment that is proposed.

An assessment should be based on the **extent** to which decision-making is affected **at the time the decision needs to be made**. The decision regarding the adult's capacity to give or refuse consent should be based on the assessment at the time rather than the existence of the adult's diagnosis or disability.

It is important to recognise that capacity is **not** an all or nothing concept – a person may **not** have capacity at a particular point in time or for a particular decision, but this does not mean that they will **never** have capacity to make any decisions. Capacity to make decisions may be diminished temporarily or permanently, partially or totally.

For example, people with dementia can retain the capacity to make decisions until the very late stages in their journey. However this ability may fluctuate from day to day and hour to hour, and this needs to be considered during assessment. The degree to which they are able to make decisions may also vary and they may be capable of deciding on their day to day treatment, but be incapable of understanding the consequences of more complex treatments, for example, surgery or chemotherapy.

Generally treatment will involve some positive action based on clinical need and in accordance with the principles ensuring that as far as possible the person who has any incapacity has the same equity of treatment and choice as a person with capacity. Therefore capacity to consent must be considered with respect **to a specific decision** and **for a given moment in time**. The person's capacity to consent to the treatment or investigation being proposed should be assessed specifically according to the clinical situation.

Assessment of Capacity under Part 5 of the Adults with Incapacity Act

Who can assess capacity?

The practitioner who has **overall responsibility** for the treatment conducts the assessment with the adult and where a person is assessed as not having capacity a 'Certificate of Incapacity' is completed that relates to the specific treatment proposed. An example of the practitioner who has overall responsibility for the treatment may be the adult's GP if they are receiving treatment at home, or the Consultant who is proposing treatment within a hospital, or the most senior doctor on duty.

If the person is assessed as not having capacity, and a certificate is completed, the practitioner then has authority to do what is reasonable in the circumstances to provide

treatment that is aimed at protecting and improving the physical or mental health of the adult.

Remember!

all decisions must be based on the principles of Adults with Incapacity (Scotland) Act 2000.

How will Incapacity be determined?

There is no single universally accepted test for determining decision-making capacity, however, many tools and instruments have been developed. Three tools regularly cited in the literature include:

- Aid to Capacity Evaluation (ACE) developed at the Joint Centre for Bioethics at the University of Toronto. http://www.jointcentreforbioethics.ca/tools/ace_download.shtml
- Assessment of Capacity for Everyday Decision-Making (ACED) developed in Pennsylvania. http://www.uphs.upenn.edu/adc/pdf/ACED%20Packet_final.pdf
- MacArthur Competence Assessment Tool – Treatment (MAC-CAT-T) developed by Department of Psychiatry, University of Massachusetts Medical School (Grisso and Applebaum, 1998).

All of these tools have limitations in practice situations and the assessment is often based on intuition and professional experience.

Where it is believed that there may be incapacity due to cognitive impairment or suspected dementia, a screening for cognitive impairment should always be undertaken. This will indicate if the person has a problem with their cognitive function but it should not be assumed that people with cognitive impairment lack capacity. This can also indicate the need for more formal assessment of cognitive function and can be repeated at appropriate intervals during the person's stay in hospital.

A brief cognitive screening tool for use in acute general hospitals is the: **Screening for Cognitive Impairment: The Four Item Abbreviated Mental Test (AMT4)**

This four Item Abbreviated Mental test has recently been found to be as effective as the 10 point AMT screening for cognitive impairment (Scottish Government 2010)[5].

AMT4

1. How old are you?
2. What is your date of birth?
3. What is this place?
4. What year is it?

A score of three or less on this scale would indicate the possible presence of cognitive impairment and should lead to a referral for further assessment.

An alternative screening tool is the 4AT. The 4AT merges components of the Short CAM, (Confusion Assessment Method) and the AMT4, both of which have been previously validated (**See appendix 3**).

There are however, very specific additional requirements for the assessment of capacity when it relates to consent for medical treatment under Part 5 of the Act. It must be determined whether the person:

- Is capable of making and communicating their choice.
- Understands the nature of what is being asked and why.
- Has memory abilities that allow the retention of information.
- Is aware of any alternatives.
- Has knowledge of the risks and benefits involved.
- Is aware that such information is of personal relevance to them.
- Is aware of their right to, and how to, refuse, as well as the consequences of refusal.
- Has ever expressed their wishes relevant to the issue when greater capacity existed.
- Is expressing views consistent with their previously preferred moral, cultural, family, and experiential background.
- Is not under undue influence from a relative, carer or other third party declaring an interest in the care and treatment of the adult[6].

Although the AWI act gives the medical practitioner the main responsibility to decide whether a person is capable of consenting to treatment, they are expected to use multi-disciplinary consultation as part of the overall assessment.

They **must** also apply the principles of the Act and consider the person's past and present wishes, feelings and, where reasonable and practicable, seek the views of relatives and others supporting the person.

5. Scottish Government (2010) *Validity of the 4 - item Abbreviated Mental test in Accident and Emergency. Chief Scientist Office.* Edinburgh. Available at http://www.cso.scot.nhs.uk/publications/execsumms/mayjune08/schofield.pdf
6. Scottish Government (2010) Adults with Incapacity (Scotland) Act 2000 Code of Practice for Practitioners authorised to carry out medical treatment or research under Part 5 of the Act. (Code of Practice, 2010, pp9-10). Available at www.scotland.gov.uk/Topics/Justice/law

Scenario 2

To support your understanding of the interrelationship between the legal provisions of the AWI Act and the principles in guiding the practitioners in their assessment of capacity take some time to consider James's story below and answer the questions posed.

James is a 75 year old man with a diagnosis of dementia, type 2 diabetes mellitus and peripheral vascular disease. He is admitted to hospital with a gangrenous ulcer on his left foot. The intervention recommended is below knee amputation. James is not sure if he wants to have the treatment but his son informs the doctor that he has Power of Attorney and wants his father to have the amputation as he believes this will benefit him and improve his quality of life.

Should the treatment proceed using the proxy consent from James's son?

Should James's capacity to consent to treatment be assessed?

How should the application of the principles of the AWI Act be applied in this situation?

Record your answer here ▷ (further space provided on following page.)

Please refer to Appendix 4 for suggested discussion points. ▷

Section 47 Certificate

If the practitioner believes the person is not capable they should always complete a **Section 47** certificate of incapacity which should be retained in the person's current care files accompanied by a record of ongoing assessment and review. **A copy of the Certificate is set out on the next page.** ▷

ADULTS WITH INCAPACITY
(SCOTLAND) ACT 2000

Certificate of Incapacity under Section 47 of the Adults with Incapacity (Scotland) Act 2000

I _____ (name)

of _____ (address)

*am the medical practitioner primarily responsible for the medical treatment of; or

*am a person who is *a dental practitioner/an ophthalmic optician/a registered nurse and who satisfies such requirements as are prescribed by the Adults with Incapacity (Requirements for Signing Medical Treatment Certificates) (Scotland) Regulations 2007 and who is primarily responsible for treatment of the kind in question of:

_____ (name)

of _____ (address) D D M M Y Y (date of birth)

for whom the *guardian/welfare attorney/person appointed by intervention order/nearest relative/carer

is _____

I have examined the patient named above on D D M M Y Y (date). I am of the opinion that *he/she is incapable within the meaning of the Adults with Incapacity (Scotland) Act 2000 ("the 2000 Act") in relation to a decision about the following medical treatment:

_____

because of (nature of incapacity) _____

_____

_____

This incapacity is likely to continue for _____ months.

*I therefore consider it appropriate for the authority conferred by section 47(2) of the 2000 Act to subsist from:

D D M M Y Y (date of examination) until D D M M Y Y, being a period which does not exceed one year from the *date of the examination on which this certificate is based/date of revocation of the certificate issued previously by me; or

*I am of the opinion that (a) *he/she is suffering from *a severe or profound learning disability/dementia/a severe neurological disorder; and (b) *what he/she is suffering from is unlikely to improve within the meaning of the Adults with Incapacity (Conditions and Circumstances Applicable to Three Year Medical Certificates) (Scotland) Regulations 2007/ Y Y and therefore consider it appropriate for the authority conferred by section 47(2) of the 2000 Act to subsist until:

D D M M Y Y being a period which does not exceed three years from the *date of the examination on which this certificate is based/date of revocation of the certificate issued previously by me.

The authority conferred by section 47(2) of the 2000 Act shall subsist for the period specified above or until such earlier date as this certificate is revoked.

In assessing the capacity of the patient, I have observed the principles set out in section 1 of the 2000 Act.

Signed _____ Date D D M M Y Y

*delete as appropriate

(Image provided courtesy of the Scottish Government)

What should be included in the certificate?

As well as the person's name, address and date of birth, the certificate is a 'statement' from the practitioner that they have examined the person, It must also detail:

- The lack of capacity.
- The proposed intervention.
- Who they have consulted.
- That the general principles of the AWI Act have been observed.

The certificate will state how long it is valid for and must be signed and dated. The maximum period covered by a certificate can be 3 years; however, it is recommended that it covers a shorter period dependent on circumstances.

As a certificate is treatment specific, its length should reflect this. For example, if a person attends for an endoscopy then the certificate is for that procedure and for one day. If the person's condition or circumstances change during the time the certificate is valid, then it can be cancelled altogether, or cancelled and replaced with a new certificate.

When a person requires multiple or complex healthcare interventions, it is recommended that a treatment plan be drawn up. Examples of treatment plans can be found at Annex 5 of the Part 5 Code of Practice: http://www.scotland.gov.uk/Publications/2008/06/13114117/10

What happens if there is a proxy?

If the person does not have capacity and there is a proxy such as a Welfare Attorney, Welfare Guardian or person authorised under an intervention order, they can give consent on behalf of the person and a Section 47 certificate **must** still be completed.

Treatment cannot automatically proceed if the proxy refuses consent and in such an event the practitioner with overall responsibility must contact the Mental Welfare Commission to seek a second opinion. The Mental Welfare Commission will appoint a 'Nominated Practitioner' with the relevant professional knowledge or expertise who will interview both the adult and their proxy.

If the 'Nominated Practitioner' agrees with the proxy, then treatment cannot proceed. The practitioner issuing the certificate can appeal the decision to the Court of Session. If the 'Nominated Practitioner' agrees with the practitioner who has issued the certificate of incapacity, the proxy can also appeal to the Court of Session.

In the interim, while the appeal is being dealt with, general authority to treat is withdrawn and only emergency treatment can be given to save the adult's life or prevent serious deterioration of health.

REMEMBER...
Think **Capacity**

- **Assess capacity to consent.**
- **Can the person give valid consent?**

If not.....

- Is there a proxy decision maker - i.e. Welfare Attorney or Guardian?
- Do they have the power to consent or withhold consent for medical treatment?
- Does the proposed treatment comply with the principles of the Adults with Incapacity (Scotland) Act?
- Do you need to seek further specialist advice on capacity to consent to treatment?
- A Section 47 certificate should be completed even when there is a proxy decision maker.

The following 2 scenarios are intended to allow you to explore your current thinking and responses to some more complex issues.

Please refer to appendix 4 for suggested discussion points.

Scenario 3

Charlie is a 49 year old man with a diagnosis of Down's Syndrome and lives with his parents who are both in their 80's. Charlie arrives at the hospital following a fall accompanied by his parents. He is conscious but has a suspected broken leg and needs an X–ray. He also has a deep cut to his head that may need sutures. His parents are with him and say they are his Welfare Guardians but have no paperwork confirming this.

Should Charlie be asked to give consent?

If Charlie lacks capacity, what procedure should be followed?

Is there any way of checking if Guardianship is in place?

Record your answer here ▷

Please refer to Appendix 4 for suggested discussion points. ▷

Scenario 4a

Catherine's Story Part 1

Catherine is an 80 year old lady with advanced dementia and lives in a care home where she is visited daily by her husband. She has been referred by her GP for investigation of suspected gastrointestinal cancer. Catherine attends the hospital for an endoscopy accompanied by her husband who has a Welfare Power of Attorney and has given consent for her treatment. A Section 47 certificate has been completed, but as Catherine is about to be given intravenous sedation she resists and becomes distressed.

Does the certificate authorise the use of force to carry out the procedure?

Record your answer here ▷

Please refer to Appendix 4 for suggested discussion points. ▷

Scenario 4b

Catherine's Story Part 2

The procedure is abandoned and during discussions between the doctor and Catherine's husband about continued treatment and the possibility of carrying out further investigations; the doctor informs him that he has made the clinical decision that Catherine would not be resuscitated in the event of cardiac arrest (DNACPR). Catherine's husband is angry and states that while Catherine would not want to be resuscitated it is for him as her Welfare Attorney to make this decision and not the doctor's.

Can a Welfare Attorney make a decision about resuscitation?

Record your answer here ▷

Please refer to Appendix 4 for suggested discussion points. ▷

Summary – Key Learning Points

In this learning resource we explored the concepts of capacity and consent, the process of determining capacity and how you can use the principles and provisions within the legislation to support you in your practice as well as the internal and external factors which may influence a person's ability to make a decision. The key learning points are:

- **You cannot treat a person without consent unless it is an emergency.**
- **You must assess capacity to obtain valid informed consent.**
- **Capacity is situation specific and assessment is a continuous process.**
- **Substitute decision making must be properly authorised and can only be used when incapacity is confirmed.**
- **Access to treatment must be based on clinical need not capacity to consent.**
- **You must complete a Section 47 Certificate of Incapacity.**

The medical treatment flowchart attached at **Appendix 5** sets out the procedures involved in medical decisions under Part 5 of the Adults with Incapacity (Scotland) Act 2000.

Remember: No matter how complex the issue, the appropriate application of the principles of the Adults with Incapacity (Scotland) Act 2000 will support the decision made.

Appendix 1

The following table describes the shared principles of the three pieces of Adult Protection legislation in Scotland which we need to take account of before we consider any intervention, action, or treatment.

Adults with Incapacity Act 2000	Mental Health Act 2003	Adult Support and Protection Act 2007
Benefit - The intervention must enable the person to do something which they could be reasonably expected to do if their capacity was not impaired.	**Benefit** - Any intervention under the Act should be likely to produce for the service user a benefit which cannot reasonably be achieved other than by the intervention.	**Benefit** - The intervention must enable the person in some way.
Least Restrictive Option - The intervention must balance risk versus protection and be the least restrictive on the freedom of the person.	**Least Restrictive Alternative** - Service users should be provided with any necessary care, treatment and support, both in the least invasive manner and in the least restrictive manner and environment compatible with the delivery of safe and effective care, taking account where appropriate of the safety of others.	**Least Restrictive Option** - The intervention must balance risk versus protection and be the least restrictive on the freedom of the person.
Past and Present Wishes of the Adult - This needs to take into account if it is some thing the person would have chosen to do in the past or in their present circumstances.	**Participation** - Service users should be fully involved, to the extent permitted by their individual capacity, in all aspects of their assessment, care, treatment and support. Account should be taken of their past and present wishes, so far as they can be ascertained.	**Respect for Adult's Past and Present Wishes** - Needs to take into account if it is something the person would have chosen to do in the past or in their present circumstances.
Views of Relevant Others – These must be taken account of, including family carers and others appointed to make decision on person's behalf.	**Respect for Carers** - Those who provide care to service users on an informal basis should receive respect for their role and experience, receive appropriate information and advice, and have their views and needs taken into account.	**Consider Views of Others** - These must be taken account of, including family carers and others appointed to make decision on person's behalf.
Encourage the Adult to Act - Use existing skills and develop new skills.	**Informal Care** - Wherever possible care, treatment and support should be provided to people with mental disorder without recourse to compulsion.	**Encourage the Adult to Participate** - Providing information and support to enable them to do so.
	Non Discrimination - People with mental illness should, whenever possible, retain the same rights and entitlements as those with other health needs.	**Non Discrimination** - The adult should not be treated less favourably than another adult.
	Respect for Diversity - Service users should receive care, treatment and support in a manner that accords respect for their individual qualities, abilities and diverse backgrounds and properly takes into account their age, gender, sexual orientation, ethnic group and social, cultural and religious background.	**Respect for Diversity** - The adult's abilities, background and characteristics must be taken into consideration in any intervention.

Appendix 2

Structure and Key Provisions of the Adults with Incapacity (Scotland) Act 2000

The Act is has 7 parts:

Part 1: Definitions, Roles, Responsibilities and General Principles
Part 2: Financial and Welfare Powers of Attorney
Part 3: Access to Funds
Part 4: Management of Residents Funds
Part 5: Authority to Treat
Part 6: Intervention and Guardianship Orders
Part 7: Miscellaneous Provisions

This module specifically focuses on Part 5, however, it is important to have an overall understanding of the whole Act.

Part 1. Definitions, Roles, Responsibilities and General Principles - Implemented in April 2001.

This part of the Act defines the roles of the authorities that will act under the legislation; the **Sheriff, Mental Welfare Commission**, **Local Authorities** and **Health Boards**. It also created and defined the new role of **Public Guardian** and provided for **Codes of Practice** to be developed. Most importantly, it sets out the **General Principles** that must apply to any intervention in the affairs of an adult covered by the Act.

The Public Guardian

The Office of the Public Guardian has duties to register Powers of Attorney, intervention and guardianship orders, and to give permission for the withdrawal of funds from the person's bank account. It also receives and investigates complaints and has a duty to give advice and information on request.

The Mental Welfare Commission

The Mental Welfare Commission works to safeguard the rights and welfare of people with mental illness, learning disability and other mental disorders and their duties are set out in mental health law. The Mental Welfare Commission also has a duty to enquire into any potential ill-treatment, deficiency in care or treatment, improper detention or possible loss or damage to the property of a person with mental disorders.

The Local Authority

The Local Authority has a variety of duties:

- Supervise Welfare Guardians.
- Investigate complaints and circumstances in which the personal welfare of an adult with incapacity seems to be at risk.
- Provide information and advice.
- Take the necessary steps to safeguard the property, financial affairs or personal welfare of the adult.
- Apply to the Sheriff for an intervention order for the protection of the adult's property, financial affairs or personal welfare.
- Prepare reports to accompany applications for intervention and guardianship orders.
- Apply for intervention and guardianship orders if necessary.
- Recall guardianship and intervention orders in relation to the welfare of adults.

Part 2. Financial and Welfare Powers of Attorney - Implemented in April 2001.

This part of the Act clearly defines the circumstances under which an adult, **who still has capacity to make decisions and can fully understand what they are doing.** It enables the person to safeguard their welfare or the management of their financial affairs, should their capacity deteriorate in the future, as detailed earlier in this learning resource.

Part 3. Access to Funds

- Implemented in April 2001.

This part set up a new scheme to allow access to funds belonging to an adult who lacks capacity to manage them. An individual, normally a relative or carer, can apply to the Public Guardian to gain access to accounts held either solely or jointly by the adult in banks or building societies. If the Public Guardian authorises it, the individual can then set up a designated account into which the bank will release funds as instructed, so that the money can be used to meet the adult's daily living expenses. It also allows one holder of a joint account to continue to operate the account if the other holder loses capacity to do so. The application to set up this access to funds must be accompanied by a **Certificate of Incapacity** and be counter-signed by someone who can confirm that the applicant is able to undertake these responsibilities. The Public Guardian monitors access to funds to ensure that the designated person acts within the rules laid down to safeguard the adult's interests.

Part 4. Management of Residents Funds

- Implemented October 2003.

This part of the Act allows hospital and care home managers to manage the finances of residents who lack capacity to do so themselves. These **Authorised Managers** will be able to apply to their **Supervisory Body** (either the relevant **Health Board** for NHS hospitals or the **Care Inspectorate** for registered care homes) if they need to manage a resident's funds and no other arrangements can be made. The application will need to include a **Certificate of Incapacity** and a plan of care detailing how the funds will be used to benefit the adult. If authority is granted, the managers will be able to manage funds up to a specified amount and use the money to purchase goods or services, which contribute to the adult's comfort. The Supervisory Body will strictly monitor any use of the resident's funds.

Part 5. Authority to Treat

- Implemented July 2002, reviewed in 2004 and amended with effect from October 2005.

The Act allows treatment to be given to safeguard or promote the physical or mental health of an adult who is unable to **give or refuse** consent because they lack capacity to make decisions about the specific treatment being proposed.

Part 6. Intervention and Guardianship Orders

- Implemented April 2001.

Individuals, usually relatives or carers, (or the Local Authority if no individual applicant exists) can apply to the **Sheriff Court** for a Guardianship Order or an Intervention Order as detailed earlier in this learning resource.

Part 7. Contains miscellaneous provisions

- Implemented April 2001.

This part includes a collection of sections regarding existing processes and how they are included in the Act. For example, people appointed as **Curator Bonis** and **Tutors Dative**, which were terms used previously for people who had some financial and/or welfare powers given to them by the courts. Under the Act, these people automatically became Continuing and/or Welfare Guardians.

This part also makes clear that it is an offence (punishable by up to 2 years in prison) to neglect or ill-treat an adult who lacks capacity.

Additional Safeguards

An **advance statement** sets out the way a person wishes to be treated, or not treated, for mental disorder in the event of becoming mentally unwell and unable to make decisions about their treatment. It is intended to improve the person's participation, in line with the principles of the Act and requires tribunals and others providing treatment to take account of the past and present wishes and feelings of the person. It is one potentially important way of recording these wishes. An advance statement can be made by anyone, even if they are under 16, as long as they understand what they are putting in the statement and the effect it may have on their care and treatment in the future. In order for an advance statement to be valid it must be in writing, signed and witnessed by an 'appropriate' person as outlined in the Act.

A **personal statement** can be attached to an advance statement but does not have the same effect in law. It sets out what the person would like to happen if they, for example, have to go into hospital. Things like what to tell their employer, care arrangements for pets and other domestic matters can be included. It is helpful if a personal statement is signed and dated, but there is no requirement for a personal statement to be witnessed.

Independent advocacy supports a person's right to have their own voice heard in decisions made about their health and well being if, for whatever reason, they find it difficult to put their own case to service providers, or do not feel in a strong position to exercise or defend their rights. It is particularly helpful for people who are at risk of being mistreated or ignored, or who wish to negotiate a change in their care, or are facing a period of crisis. The Act makes it a right for people who have a mental disorder and places a duty on NHS Boards to ensure it is provided.

Appendix 3

4AT

The 4A Test: screening instrument for cognitive impairment and delirium

(Label)
Patient name:
Date of birth:
Patient number:

.....

Date: Time:
Tester:

CIRCLE

[1] ALERTNESS

This includes patients who may be markedly drowsy (eg. difficult to rouse and/or obviously sleepy during assessment) or agitated/hyperactive. Observe the patient. If asleep, attempt to wake with speech or gentle touch on shoulder. Ask the patient to state their name and address to assist rating.

Normal (fully alert, but not agitated, throughout assessment)	0
Mild sleepiness for <10 seconds after waking, then normal	0
Clearly abnormal	4

[2] AMT4

Age, date of birth, place (name of the hospital or building), current year.

No mistakes	0
1 mistake	1
2 or more mistakes/untestable	2

[3] ATTENTION

Ask the patient: "Please tell me the months of the year in backwards order, starting at December." To assist initial understanding one prompt of "what is the month before December?" is permitted.

Months of the year backwards	Achieves 7 months or more correctly	0
	Starts but scores < 7 months / refuses to start	1
	Untestable (cannot start because unwell, drowsy, inattentive)	2

[4] ACUTE CHANGE OR FLUCTUATING COURSE

Evidence of significant change or fluctuation in: alertness, cognition, other mental function (eg. paranoia, hallucinations) arising over the last 2 weeks and still evident in last 24hrs

No	0
Yes	4

4 or above: possible delirium +/- cognitive impairment
1-3: possible cognitive impairment
0: delirium or cognitive impairment unlikely (but delirium still possible if [4] information incomplete)

4AT SCORE ☐

GUIDANCE NOTES

The 4AT is a screening instrument designed for rapid and sensitive initial assessment of cognitive impairment and delirium. A score of 4 or more *suggests* delirium but is not diagnostic: more detailed assessment of mental status may be required to reach a diagnosis. A score of 1-3 suggests cognitive impairment and more detailed cognitive testing and informant history-taking are required. Items 1-3 are rated *solely on observation of the patient at the time of assessment*. Item 4 requires information from one or more source(s), eg. your own knowledge of the patient, other staff who know the patient (eg. ward nurses), GP letter, case notes, carers. The tester should take account of communication difficulties (hearing impairment, dysphasia, lack of common language) when carrying out the test and interpreting the score.

Alertness: Altered level of alertness is very likely to be delirium in general hospital settings. If the patient shows significant altered alertness during the bedside assessment, score 4 for this item. **AMT4 (Abbreviated Mental Test - 4):** This score can be extracted from items in the full AMT if done immediately before. **Acute Change or Fluctuating Course:** Fluctuation can occur without delirium in some cases of dementia, but marked fluctuation usually indicates delirium. To help elicit any hallucinations and/or paranoid thoughts ask the patient questions such as, "Are you concerned about anything going on here?"; "Do you feel frightened by anything or anyone?"; "Have you been seeing or hearing anything unusual?" In general hospital settings psychotic symptoms most often reflect delirium rather than functional psychosis (such as schizophrenia).

Confusion Assessment Method (CAM)

(Adapted from Inouye et al., 1990)

Patient's Name: _____ Date: _____

Instructions: Assess the following factors.

Acute Onset

1. Is there evidence of an acute change in mental status from the patient's baseline?

___ YES ___ NO ___ UNCERTAIN ___ NOT APPLICABLE

Inattention

(*The questions listed under this topic are repeated for each topic where applicable.*)

2A. Did the patient have difficulty focusing attention (for example, being easily distractible or having difficulty keeping track of what was being said)?

_____ Not present at any time during interview

_____ Present at some time during interview, but in mild form

_____ Present at some time during interview, in marked form

_____ Uncertain

2B. (*If present or abnormal*) Did this behavior fluctuate during the interview (that is, tend to come and go or increase and decrease in severity)?

___ YES ___ NO ___ UNCERTAIN ___ NOT APPLICABLE

2C. (*If present or abnormal*) Please describe this behavior.

_____

_____

Disorganized Thinking

3. Was the patient's thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable, switching from subject to subject?

___ YES ___ NO ___ UNCERTAIN ___ NOT APPLICABLE

Altered Level of Consciousness

4. Overall, how would you rate this patient's level of consciousness?

_____ Alert (*normal*)

_____ Vigilant (*hyperalert, overly sensitive to environmental stimuli, startled very easily*)

_____ Lethargic (*drowsy, easily aroused*)

_____ Stupor (*difficult to arouse*)

_____ Coma (*unarousable*)

_____ Uncertain

1

Disorientation

5. Was the patient disoriented at any time during the interview, such as thinking that he or she was somewhere other than the hospital, using the wrong bed, or misjudging the time of day?

___ YES ___ NO ___ UNCERTAIN ___ NOT APPLICABLE

Memory Impairment

6. Did the patient demonstrate any memory problems during the interview, such as inability to remember events in the hospital or difficulty remembering instructions?

___ YES ___ NO ___ UNCERTAIN ___ NOT APPLICABLE

Perceptual Disturbances

7. Did the patient have any evidence of perceptual disturbances, such as hallucinations, illusions, or misinterpretations (for example, thinking something was moving when it was not)?

___ YES ___ NO ___ UNCERTAIN ___ NOT APPLICABLE

Psychomotor Agitation

8A. At any time during the interview, did the patient have an unusually increased level of motor activity, such as restlessness, picking at bedclothes, tapping fingers, or making frequent, sudden changes in position?

___ YES ___ NO ___ UNCERTAIN ___ NOT APPLICABLE

Psychomotor Retardation

8B. At any time during the interview, did the patient have an unusually decreased level of motor activity, such as sluggishness, staring into space, staying in one position for a long time, or moving very slowly?

___ YES ___ NO ___ UNCERTAIN ___ NOT APPLICABLE

Altered Sleep-Wake Cycle

9. Did the patient have evidence of disturbance of the sleep-wake cycle, such as excessive daytime sleepiness with insomnia at night?

___ YES ___ NO ___ UNCERTAIN ___ NOT APPLICABLE

Scoring:

For a diagnosis of delirium by CAM, the patient must display:

1. Presence of acute onset and fluctuating discourse

AND

2. Inattention

AND EITHER

3. Disorganized thinking

OR

4. Altered level of consciousness

Source:

Inouye SK, van Dyck CH, Alessi CA, Balkin S, Siegal AP, Horwitz RI. Clarifying confusion: the confusion assessment method. A new method for detection of delirium. *Ann Intern Med.* 1990;113(12):941-948.

Confusion Assessment Method (CAM) Diagnostic Algorithm

Feature 1: Acute Onset and Fluctuating Course

This feature is usually obtained from a family member or nurse and is shown by positive responses to the following questions: Is there evidence of an acute change in mental status from the patient's baseline? Did the (abnormal) behavior fluctuate during the day; that is, did it tend to come and go, or increase and decrease in severity?

Feature 2: Inattention

This feature is shown by a positive response to the following question: Did the patient have difficulty focusing attention; for example, being easily distractible, or having difficulty keeping track of what was being said?

Feature 3: Disorganized Thinking

This feature is shown by a positive response to the following question: Was the patient's thinking disorganized or incoherent, such as rambling or irrelevant conversation, unclear or illogical flow of ideas, or unpredictable switching from subject to subject?

Feature 4: Altered Level of Consciousness

This feature is shown by any answer other than "alert" to the following question: Overall, how would you rate this patient's level of consciousness? (alert [normal], vigilant [hyperalert], lethargic [drowsy, easily aroused], stupor [difficult to arouse], or coma [unarousable])

Source:

Inouye SK, van Dyck CH, Alessi CA, Balkin S, Siegal AP, Horwitz RI. Clarifying confusion: the confusion assessment method. A new method for detection of delirium. *Ann Intern Med.* 1990;113(12):941-948.

Appendix 4

Suggested discussion points

Scenario 1

How do you think the Act can be used to aid decision making in this situation?

A decision cannot be based on assumptions that Edith lacks capacity because she has a diagnosis of dementia, without assessing her capacity to consent to treatment. It is important to ensure that a person's right of equality of access under the Equality (Act 2010) is upheld. An assessment of capacity should be carried out and the medical practitioner should look at how Edith can be supported to comply with post operative instructions.

Through discussions with Edith, her family, supporters and her GP, consideration needs to be taken of what her support needs are, and how they can be met. For example, it may be that Edith has capacity to follow the post operative regime, or she may need prompting from a family member or other supporter. The instructions could be provided in a different format if necessary such as audio rather than written. A range of telehealthcare supports could also be put in place to aid memory.

Additional considerations are needed in relation to risk factors associated with anaesthesia such as attention to pre and post-operative care, particularly hydration that will speed recovery as well as the need to avoid specific medications. For example, anticholinergics and benzodiazepine. Recognising the need for pain relief, both pre and post operatively, is also particularly important if the person has dementia. They may not be able to verbally communicate that they are in pain and the experience of pain can cause distress, impair memory and delay recovery.

Where a decision to withhold or withdraw treatment that has the potential to prolong life is being considered, doctors should consult the BMA (2007) guidance.

Scenario 2

Should the treatment proceed using the proxy consent from James's son?

When James's son informs you he has Power of Attorney and he can consent to treatment, you should ask to see a copy of the Certificate of Registration issued by the Public Guardian before he can give consent. You need to be assured that it is a Welfare Power of Attorney and not a Continuing Power of Attorney and that it contains the relevant specified authority to make this decision.

Should James's capacity to consent to treatment be assessed?

You should carry out an assessment of capacity because even though James has dementia, he may still be able to consent to treatment. This will still be necessary even if you find out James's son has a Welfare Power of Attorney as these powers do not come into force until the person has lost capacity.

How should the application of the principles of the AWI Act be applied in this situation?

The principles that may apply here are benefit, past and present wishes, views of relevant others, and, encouraging the person to act.
Remember, you have to prove incapacity; the individual is not required to prove their capacity. The starting point for assessing someone's capacity to make a particular decision is always the assumption that the individual has capacity. In legal proceedings, the burden of proof will fall on the person who asserts that capacity is lacking.

Scenario 3

Should Charlie be asked to give a valid consent to treatment?

You should routinely assess capacity to consent to treatment and if Charlie has the capacity to make his own decisions about treatment, then the same procedure should be followed as for any other patient. Even if his parents are guardians, the medical practitioner cannot automatically complete a Section 47 certificate without assessing capacity. Remember, it might also be the case that he can consent to some, but not all, aspects of his medical care and treatment.

If Charlie lacks capacity, what procedure should be followed?

If he lacks capacity, then the medical practitioner must follow the procedure set out in Part 5. This involves carrying out an assessment of his capacity to make a specific decision, then completing a Section 47 certificate authorising the intervention. You should not rely on anyone advising you that they are the guardian without seeing paperwork. In this case there is no disagreement between the parents / guardians and the medical team so there is no reason not to proceed.

Is there any way of checking if Guardianship is in place?

At the moment, there is no public register that can be checked due to confidentiality and data protection concerns. However guardians are encouraged to advise GPs, and any other interested parties and should be happy to a copy of the order.

Scenario 4

Does the certificate authorise the use of force to carry out the procedure?

Section 47(7) of the Act prohibits the use of force or detention unless it is immediately necessary. The interpretation of this will depend on the particular circumstances of each case, but the degree of force used must always be the minimum necessary. Further discussion on the use of force can be found in the MWC guidance "Right to Treat".
http://www.mwcscot.org.uk/media/51822/Right%20to%20Treat.pdf

We need to remember that hospitals can be very disorientating and frightening for a person with dementia. Additional time taken in advance to get to know Catherine and what is likely to cause her distress will help prevent this situation arising. Frequent reassurances and information to help her understand what is happening, as well as having her husband present will help make the experience less distressing. **However, it may be that because of her degree of distress, the procedure would need to be abandoned.**

For further information on suggested approaches to communication and reducing distress, access the NES Dementia Care in Acute General Hospital Settings Learning Resource
http://www.nes.scot.nhs.uk/media/350872/acute_dementia_interactive_2011.pdf

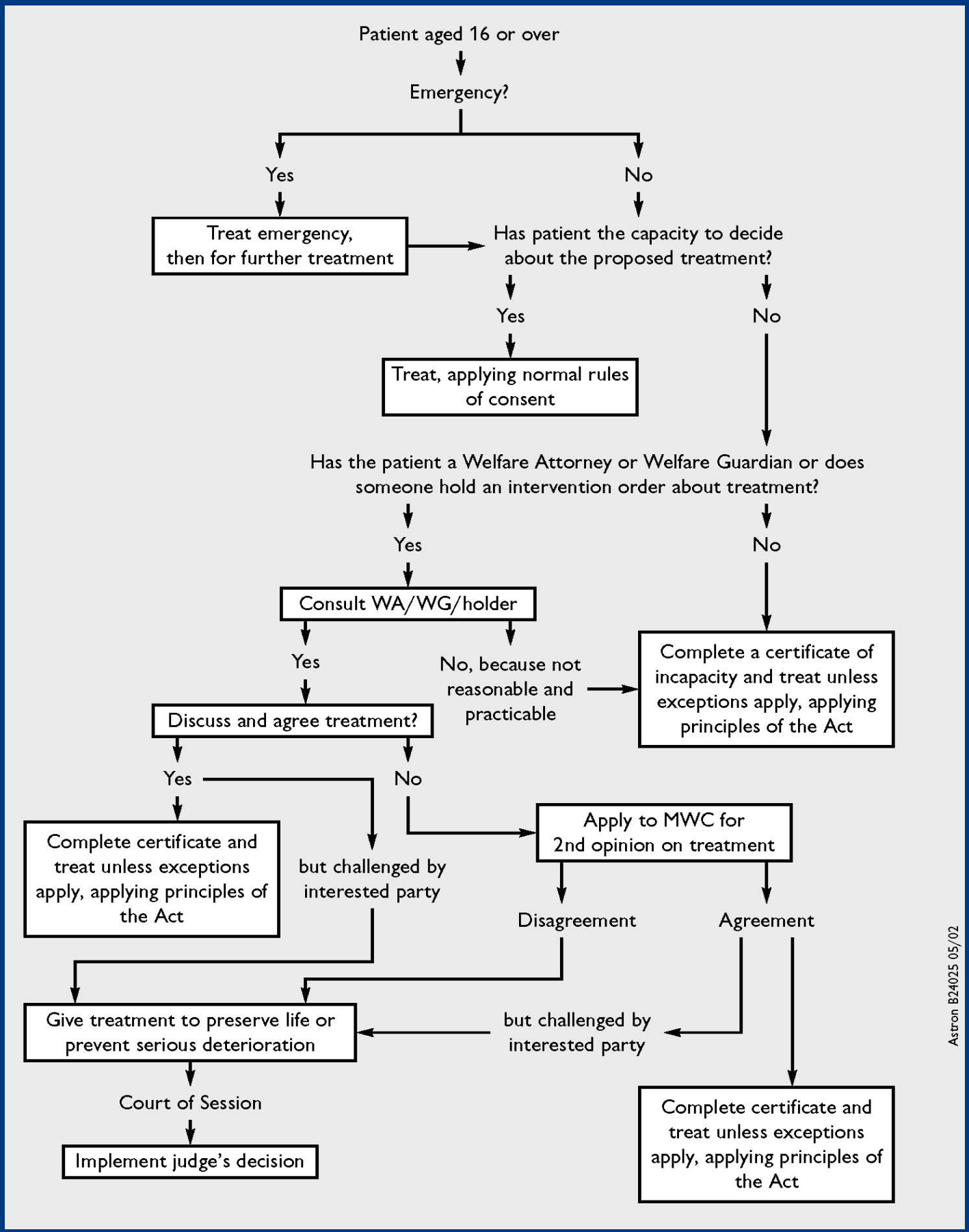
Can a Welfare Attorney make a decision about resuscitation?

Where a Welfare Attorney/Welfare Guardian/person appointed under an intervention order has been previously established for the person who lacks capacity to make a decision about resuscitation; this proxy should be approached and supported to be involved in the decision-making process. They can make an advance refusal of CPR for the person and accept or consent to CPR if this is realistically judged by the senior clinician to be likely to achieve sustainable life for the person. They cannot demand CPR if it is clear that it would not be successful in achieving sustainable life for the person and if agreement cannot be reached a second opinion should be accessed.

A diagnosis of dementia is not an automatic criterion for a decision of DNACPR.

Where there is no proxy decision maker, responsibility for the decision lies with the lead clinician. While family and carers do not have decision making rights they should be consulted to clarify the person's views prior to incapacity. It is essential that a DNACPR form is accurately completed, accessible in the person's records and communicated to all health and social care professionals, including those external to the hospital when the person is transferred. For further information access the Scottish Government's, *Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): Integrated Adult Policy: Decision Making and Communication*
www.scotland.gov.uk/Publications/2010/05/24095633/0

Adults with Incapacity (Scotland) Act 2000 Part 5: Medical Treatment - Flowchart.



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NHS Education for Scotland
Thistle House
91 Haymarket Terrace
Edinburgh
EH12 5HD

tel: 0131 313 8000
www.nes.scot.nhs.uk