

SELF-NEGLECT, CAPACITY & REFUSAL OF CARE

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Relevant Legal Frameworks

- European Convention on Human Rights provides, the right to liberty and security (article 5) and the right to respect for private and family life (article 8), along with the principle of proportionality and the existence of procedural safeguards in circumstances where rights may be infringed.
- Mental Capacity Act (2005)
- Care Act (2014) – both s9 which triggers a LA assessment of care and support needs and s42 Safeguarding Adults enquiry

Consenting to or refusing care?

- For consent to be valid, it must be voluntary and informed, and the person consenting must have the capacity to make the decision. **Voluntary:** the decision must be made alone, and must not be due to pressure by medical staff, friends or family.
- **Informed:** the person must be given full information about what the treatment involves, including the benefits and risks, whether there are reasonable alternative treatments, and what will happen if treatment does not go ahead. Staff should not withhold information just because it may upset or unnerve the person.
- **Capacity:** the person must be capable of giving consent, which means they understand the information given to them and they can use it to make an informed decision.

Consenting to or refusing care?

- A person who has the capacity to make voluntary and informed decisions for themselves about their medical treatment is legally entitled to accept or refuse any treatment that is offered to them. This decision must be respected even if the decision could result in their death.
- No person has the authority to give or withhold consent on behalf of another person over the age of 18.
- Family members do not have the legal right to be involved in a decision to accept or refuse care unless
 1. P has capacity and is consenting to them being informed and contributing to decision-making *or*
 2. P's capacity to consent has been assessed and it has been determined that they lack capacity and P's family are consulted as part of the Best Interests decision-making process

Consent to or refusal of care:

Consent should be given to the staff directly responsible for the person's current treatment, such as the nurse arranging a blood test, the GP prescribing new medication or the surgeon planning an operation.

It can be given:

- verbally
- non-verbally, for example, raising a hand to indicate they are happy for a nurse to take a blood sample
- in writing, by signing a consent form
- If someone is going to have major medical intervention, such as an operation, their consent should be obtained well in advance so they have plenty of time to study any information about the procedure and ask questions
- **Note compliance is not consent!**

Mentally competent person

- The mentally competent person understands the consequences of their decisions and makes a conscious and voluntary decision to engage in acts that threaten his / her health or safety as a matter of personal choice
- May have an important high profile job - but exhibit late presentation of illness to health professionals, their poor engagement may be driven by a fear-of authority or of their own demise and once they engage they may demonstrate limited concordance with Care Plan!

GMC guidance to medics: (58-60)

- You must respect a competent patient's decision to refuse an investigation or treatment, even if you think their decision is wrong or irrational.
- You may advise the patient of your clinical opinion, but you must not put pressure on them to accept your advice.
- You must be careful that your words and actions do not imply judgement of the patient or their beliefs and values.

Essential that:

Practitioners have confidence in:

1. understanding mental capacity in relation to the refusal of medical treatment
2. the importance of recording both a service user's decision and their capacity to refuse treatment,
3. Recording a brief overview of what discussions took place to ensure that the Service User was making an informed choice when refusing.

Who refuses care?

Those living with

- addictions – alcohol, substance misuse
- Mental Illness
- Hoarding difficulties/behaviours
- Terminal illnesses

• Can you intervene and if so how?

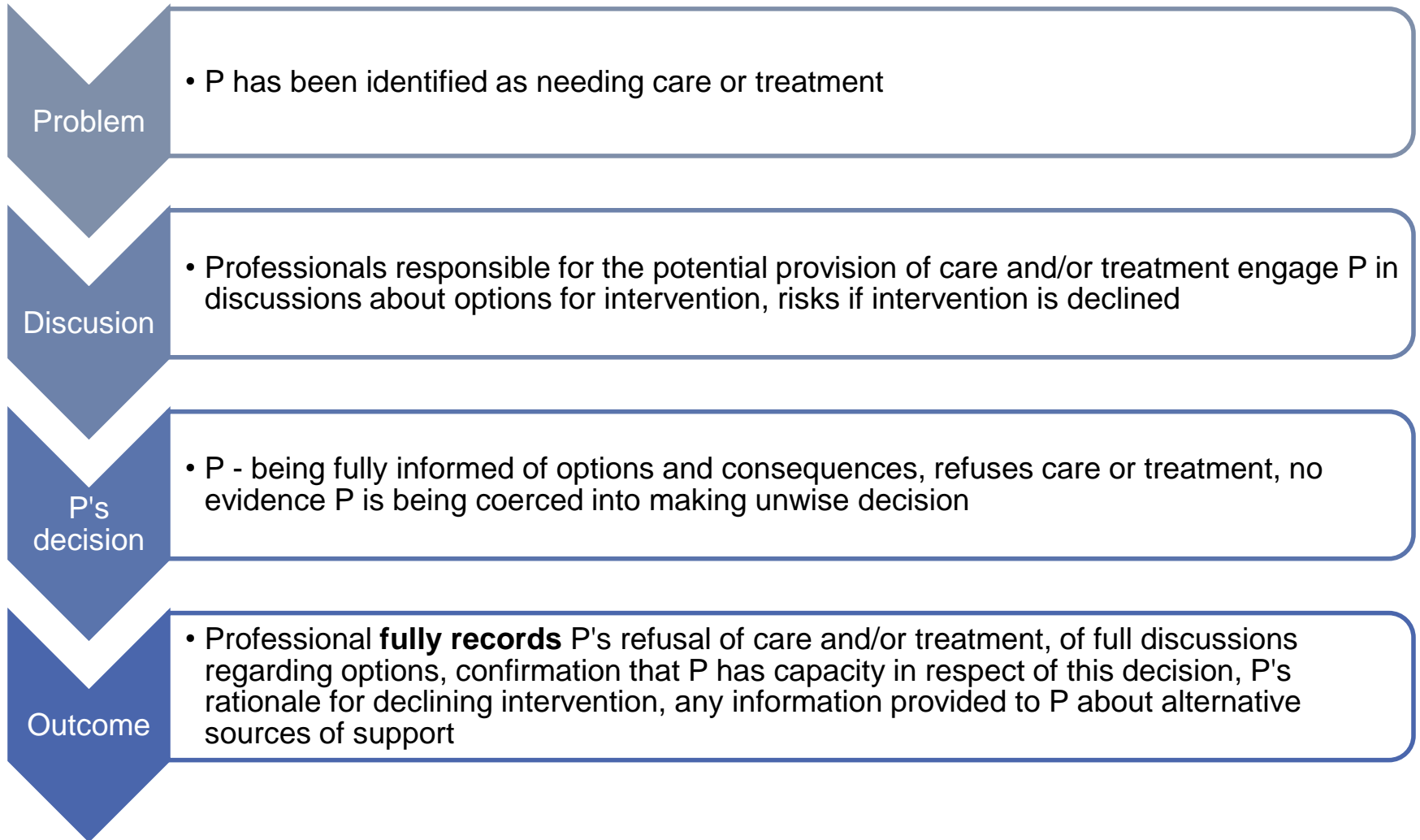
- The MHA (1983) does not enable the lawful detention of an individual with an addiction such as alcoholism unless they have an underlying mental disorder. They may be detained under s2 MHA to allow assessment (for up to 28 days) but unless this assessment concludes there is an underlying mental disorder then they will have the lawful right to be discharged !
- Often people who self-neglect do not want help to change, which puts themselves and others at risk, for example through vermin infestations, poor hygiene, or fire risk from hoarding.
- This can result in considerable distress to their families/carers. Multi-agency work and work with carers/families should be ongoing despite the refusal of P to engage

Refusing Care

If P does have capacity and is refusing care, this decision should be from a position where practitioners are confident P has been fully informed of and is able to discuss

- The choices available to them
- The consequences of those choices – including the risks of not engaging

A process if P has capacity:



Mental Capacity

- Capacity is clearly defined in the MCA (2005)
- MCA (2005) includes 5 Principles – 2 are key to this debate:
 1. presumption of capacity for everyone age 16 and over
 2. Right to make an unwise decision
- Everyone makes unwise decisions.
- *It is not the task of the courts to prevent those who have the mental capacity to make rational decisions from making decisions which others may regard as rash or irresponsible', After-all many people make rash and irresponsible decisions but are full of capacity.* (Masterman-Lister v Brutton [2002] EWHC QBD 417 (High Court); [2002] EWCA Civ 1889).

Mental Capacity

To lack capacity P will have an impairment or disturbance of the mind or brain which prevents P from making a decision due to P's inability to

- understand information relevant to the decision *and/or*
- retain *and/or*
- weigh up the pros and cons *and/or*
- communicate a decision

Executive capacity

- Executive dysfunction – is the inability to perform activities of daily living, even though the need for them may be understood – is seen as significant, and when this is accompanied by an inability to recognise unsafe living conditions, self-neglect may be the result.
- Mental capacity however involves not only the ability to understand the consequences of a decision, known as decisional capacity, but also the ability to execute the decision, known as executive capacity.
- The mental capacity assessment should entail both the ability to make a decision in full awareness of its consequences and the capacity to carry it out.

A process if there are concerns about P's capacity:

Problem

- P has been identified as needing care or treatment

Discussion

- Professionals responsible for the potential provision of care and/or treatment engage P in discussions about options for intervention, risks if intervention is declined - they conclude they have doubts about P's capacity

Capacity Assessment

- P's capacity is assessed in accordance with the MCA (2005)

Outcome

- Professional **fully records** P's assessment of capacity and outcome
- Is there a donee of LAP(PW)
- Has P made a valid/applicable advance decision
- Where conclusion is that P lacks capacity to consent then: decision can be made by professional in P's Best Interests following a Best Interests Decision-Making meeting where P's family may be consulted and other professionals involved in the care of P. P's wishes and feelings must be taken into account. Have you engaged an IMCA to support P? Where it is a complex decision, the decision may need to be heard in the Court of Protection

A quick reality check:

- If P is declining or refusing care and or treatment **why would they agree to engage in an assessment of their capacity?**
Robust record keeping is essential (s9(5) and s9(4) Care Act
- Transparency and time are essential in effective communication about risks
- P may not be willing to engage with statutory services or the NHS but may be willing to be signposted to and to engage with 3rd sector organisations
- *‘The best outcomes in self-neglect result from working closely with the person to understand what it means to them. Working to build a relationship with the person from the outset is a key element in this. It is essential to try to ‘find the person’ by learning what you can about their life history and social, economic, psychological and physical situation’ (RIPFA- self neglect)*

Where there is an issue about capacity to consent:

- A person must be assumed to have capacity unless it is established that he lacks capacity: s.1(2).
- A person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain: s.2(1).
- The question of whether a person lacks capacity must be decided on the balance of probabilities: s.2(4).
- A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success: s.1(3)
- A person is not to be treated as unable to make a decision merely because he makes an unwise decision: s.1(4).

Making a decision in a person's best interests:

- Where a person is unable to make a decision for himself, there is an obligation to act in his best interests: s.1(5).
- Where a decision relates to life-sustaining treatment, the person making the decision must not be motivated by a desire to bring about death: s.4(5).
- When determining what is in a person's best interests, consideration must be given to all relevant circumstances, to the person's past and present wishes and feelings, to the beliefs and values that would be likely to influence his decision if he had capacity, and to the other factors that he would be likely to consider if he were able to do so: s.4(6).
- So far as reasonably practicable, the person must be permitted and encouraged to participate as fully as possible in any decision affecting him: s.4(4)

Best Interests:

- A social construct
- A balance sheet approach
- Absolute necessity to consult but final decision rests with decision maker
- Legal advice can always be sourced

Aintree University Hospitals NHS Trust v James [2014] AC 591:

- Every adult capable of making decisions has an absolute right to accept or refuse medical treatment, regardless of the wisdom or consequences of the decision. The decision does not have to be justified to anyone. **Without consent any invasion of the body, however well-meaning or therapeutic, will be a criminal assault.**

A presumption in favour of life?

- *The starting point is a strong presumption that it is in a person's best interests to stay alive. But this is not an absolute, and there are cases where it will not be in the patient's interests to receive life-sustaining treatment. (Aintree v James at [35]).*
- At [23], Baroness Hale noted that the Act gives limited guidance about best interests. Every case is different [36].
- At [39], she said this:
"The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be."
- As Baroness Hale put it at [44-45], *the purpose of the best interests test is to consider matters from the patient's point of view. Where a patient is suffering from an incurable disability, the question is whether he would regard his future life as worthwhile. As was made clear in Re J [1991] Fam 33, it is not for others to say that a life which a patient would regard as worthwhile is not worth living*

Wye Valley NHS Trust v Mr B 2015

EWCOF 60

- Mr B has schizoaffective disorder with psychotic symptoms (this has not responded to treatment), and diabetes. He requires amputation of his foot in order to save his life. Without amputation he will probably die as a result of septicemia. Mr B lacked capacity to make a decision about the amputation but consistently stated he did not wish to have the operation.
- In the judgment on 28/09/2015, Mr Justice Parker ruled that Mr B should not be operated on, taking into account Mr B's religious views, his past wishes and feelings and noting that there were major concerns that the quality of his future life was not one Mr B wished to live.

Application of ruling from Aintree University Hospital NHS Foundation Trust v James [2013] UKSC 67

- A NHS Trust v Ms X [2014] provides an example of the application of the principles of Aintree v James . In this case the NHS Trust sought declarations that it was not in Ms X's best interests to be subject to further compulsory detention and treatment of her anorexia nervosa, whether under the Mental Health Act 1983 or otherwise, notwithstanding that such treatment may prolong her life and secondly that it was in her best interests, and should be declared lawful, for her treating clinicians not to provide Ms X with nutrition and hydration with which she does not comply. Cobb J considered Ms X's welfare in the widest sense before ruling that the relief sought by the Trust would be in Ms X's best interests.

M v Mrs N & Ors [2015] EWCOP 59

- Mrs N suffered from Multiple Sclerosis and had, over the years, declined to a state in which she remained sentient but could not respond to any external stimulus or enjoy any interaction with the outside world.

Her daughter, M, brought the application. Perhaps unusually, she applied for her mother's treatment to be withdrawn. Hayden J had regard to the factors listed in section 4 Mental Capacity Act 2005, but found the crucial factor in this case to be N's past wishes and feelings. N had been a strong character, full of life, and had felt horrified when the health of her own parents had deteriorated.

While this decision was founded on Mrs N's wishes and feelings under the Mental Capacity Act, there is some overlap with the still-controversial subject of assisted suicide. Hayden J cited with implicit approval a passage from Lady Hale's judgment in the right to die case ***R (Purdy) v DPP***, and distanced himself from "what is often referred to as the sanctity of life" or "the intrinsic value of life".

“Mrs Sparkle” -*Kings College NHS Foundation Trust v C and V* [2015] EWCOP 59

- C was a woman who spent the money of four husbands and several lovers, and devoted herself to living a life that “sparkles”. She attempted suicide by washing down painkillers with champagne as she did not wish to receive treatment for her breast cancer. Despite the positive prognosis, and two out of three assessments concluding that C lacked capacity, MacDonald J ruled that C did have capacity to refuse dialysis.
- C refused to consent to dialysis and much of the treatment associated with it. She was supported in that decision by her family, and in particular her two elder daughters G and V, who considered that she had the requisite capacity.
- Macdonald J accepted that the strength and individuality of a woman’s character in life can be grounds to respect her autonomy at the point of her death. In the case of C it was her choice (and not just her wishes) that held sway.

The challenge - achieving a balance between:

- Empowerment

- Protection

It is not necessarily about minimising risks – but about balance –

In *Local Authority X v MM* [2007] EWHC Fam 2003, Munby J observed
‘what good is it making someone safer if it merely makes them miserable?’ –

this case related to a vulnerable woman’s sexual relationship with her boyfriend – a sexual relationship it was ruled she had capacity to consent to and which was of benefit to her but also carried a number of risks in relation to her mental health and to matters on which she lacked capacity to decide.

Exceptions:

- Exceptions occur where statutory authority exists which allows a clinician to override a person's treatment decision –
- P is detained under Mental Health Act 1983,
- P lacks capacity to consent to or refuse care and care or treatment is provided in their best interests under the various provisions of the Mental Capacity Act 2005
- If P lacks capacity to consent to or refuse care and has previously appointed an individual as a donee of a personal welfare Lasting Power of Attorney, the donee of LPA (PW) can consent to medical treatment on behalf of another.
- P has not previously made a valid applicable advance decision to refuse the precise treatment which is now considered to be in P's best interests

Options for intervention without consent?

- Its an emergency – life saving – s6.35 MCA Code of Practice enables clinicians to intervene to save life or prevent serious harm – but must be followed with immediate application to Court of Protection if P (though lacking capacity) is objecting
- Mental Capacity Act (2005)
- Deprivation of Liberty Safeguards – does NOT authorise care or treatment
- Mental Health Act (1983)
- Are there risks to others – Environmental Health? Public Health – eg P is self neglecting and has TB?
- Court of Protection – (if there are doubts about P's capacity)

Self-neglect & capacity

- Often many decisions not just one – each decision will require a separate assessment of capacity

References

- NHS choices – consent to treatment
<http://www.nhs.uk/Conditions/Consent-to-treatment/Pages/How-does-it-work.aspx>
- **Relevant legal terms**
- **The Mental Health Act (1983)** sets out various legal rights that apply to people with severe mental health problems. The Act also contains the powers which enable some patients to be compulsorily detained in hospital.
- **The Mental Capacity Act (2005)** is designed to protect people who cannot make decisions for themselves. The Act explains when a person is considered to be lacking capacity, and how decisions should be made in their best interests.
- **The Court of Protection** is the legal body that oversees the operation of the Mental Capacity Act (2005).

References:

- www.gmc-uk.org/guidance.
- Airedale NHS Trust v Bland [1993] 1 All ER 821;
- Re JT (Adult: Refusal of Medical Treatment) [1998] 1 FLR 48 and
- Re AK (Medical Treatment: Consent) [2001] FLR 129.
- For example, many Jehovah's Witnesses have strong objections to the use of blood and blood products, and may refuse them even if they may die as a result. Hospital liaison committees established by the Watch Tower Society (the governing body of Jehovah's Witnesses) can advise on current Society policy. They also keep details of hospitals and doctors who are experienced in 'bloodless' medical procedures.
- The consent of one parent is sufficient see Re N (A child: Religion: Jehovah's Witness) [2011] EWHC 3737 (Fam).

References:

- Braye, S; Orr, D; Preston-Shoot, M. (2015) '*Working with people who self-neglect*' Research in Practice for Adults. www.ripfa.org.uk, Dartington, Devon
- Aintree University Hospitals NHS Trust v James [2014] AC 591
- Wye Valley NHS Trust v Mr B 2015 EWCOP 60
- M v Mrs N & Ors [2015] EWCOP 59
- Mrs Sparkle” -Kings College NHS Foundation Trust v C and V [2015] EWCOP 59

Legal Options:



Microsoft Word
Document