

# Ethical dilemmas at the end of life: What does law provide us with?

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# The ethics of end of life care in practice

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- The analysis of ethical issues at the end of life has been a central component of the field of medical ethics for decades. Currently the focus is on:
  - Planning care trajectories towards the end of life
  - Decision-making and supports at the very end of life
  - The role and limits of professionals in bringing about death

# The legal regulation of ethical considerations

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- **Criminal law**

- Establishing the boundaries of permissibility in bringing about a person's death: the unlawfulness of euthanasia and assisted dying in England

- **Civil law**

- The role of the Mental Capacity Act 2005 in regulating principles for decision-making for people close to the end of life, including advance decision-making

- **Human rights law**

- Safeguarding the rights of people close to the end of life – this area of law sits in uneasy (and often unclear) relationship with the other legal regulatory frameworks

# The MCA under the microscope

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- The MCA:
  - Defines what it means to lack capacity
  - Provides formal procedures for advance decision-making
  - Provides, for the first time in English law, the possibility of proxy consent for adults
  - Governs concept of ‘best interests’
- When the MCA was first passed in 2005, it was taken to be an important, empowering, person-centred, rights-enhancing piece of legislation
- **However... that reputation has increasingly come under challenge**

# 2 challenges to the MCA's framework

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- 1. Concerns about the under-protection of adults with impairments**
  - a) Capacity, coercion and the need for an additional legal jurisdiction to safeguard 'vulnerable adults'
  - b) Deprivations of liberty and the inadequacy of the current statutory framework
  
- 2. Concerns about the over-protection of adults with impairments**
  - a) The requirements of the UN Convention on the Rights of Persons with Disabilities (UNCRPD)
  - b) End of life care and the ratification of decision-making

# Under-protection 1: Safeguarding 'vulnerable adults'

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- The MCA permits substitute decision-making only when a person is judged to lack mental capacity
- In practice, situations arise (including at the end of life) where the person has capacity, but there exists a strong intuition that intervention in the person's best interests is necessary
- Circumstances of relational abuse, manipulation and undue influence – or when there is an identified risk of such circumstances arising
- Post-2007, if the person had mental capacity and withheld consent from external support or intervention, there was no legal grounds to do anything. This did not last long...

# Under-protection 1: Safeguarding 'vulnerable adults'

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- A new regulatory framework has emerged – the so-called 'vulnerable adult jurisdiction' using the High Court's inherent jurisdiction
  - Addressed a '**jurisdictional hinterland**' outside the borders of the MCA
- Court-authorized interventions to **address coercion, constraint or undue influence in decision-making** have been endorsed – restrictions can be imposed to enable the person to choose 'free' of the relational influence – *DL v A Local Authority & Others* [2012]
- **The aim is to preserve free choices** - interventions only justified when evidence of choices being coerced or constrained
- The attempt to introduce new interventions powers to safeguard 'vulnerable adults' did not form part of the *Care Act 2014*.

# Under-protection 2: Deprivation of Liberty Safeguards

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- Widespread acknowledgement in law and practice that **the DoLS are unwieldy, bureaucratic - and that they fail to safeguard liberty appropriately**
  - Conflict of interest between the applicant and authorizer of a DoLS
  - Misuse of 'urgent applications' due to time pressures in residential placements
  - Repetition of assessment and sense of DoLS being a 'rubber stamp'
  - a person's wishes and feelings are underplayed relative to risk concerns
- *P v Cheshire West* [2014] – deprivation of liberty should not be judged relative to the particular circumstances of the person's life, the availability of alternative service provision, or the degree of impairment
- Led to a 10x increase in one year in the number of DoLS applications



# Under-protection 2: Deprivation of Liberty Safeguards

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- Law Commission (2017) *Report 372: Mental Capacity and Deprivation of Liberty* called for the replacement of DoLS with new **Liberty Protection Safeguards (LPS)**.
- The LPS seek to remove aspects of DoLS that are inefficient and that function in practice to act against the person's interests
- **Main point:** removes link between DoLS and particular care settings: encouraging LPS to form part of advance care planning such that a range of options can be considered – whether necessary and proportionate
- LPS authorizes care arrangements NOT a deprivation of liberty – and it is the provider of care arrangements not a local authority who is the authorizer
- In March 2018, the government accepted most of the proposals

# Over-protection 1: The MCA and the UNCRPD

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- The UNCRPD as an international treaty, ratified by the UK, poses significant challenges to safeguarding human rights within current mental capacity law
- Article 12 – “equal recognition before the law”:
  - **Mental capacity:** decision-making abilities that might act as thresholds for justifiable legal interventions (e.g. under the MCA)
  - **Legal capacity:** the ability to hold legal rights and duties, and to exercise those rights and duties. Deficits in mental capacity must not be used to justify denying legal capacity
- UNCRPD General Comment 1 on Article 12:
  - Support in the exercise of legal capacity must respect the rights, **will and preferences** of people with disabilities, **and should never amount to substitute decision-making**
  - When it is not practicable to determine ‘will and preferences’, the **‘best interpretation of will and preferences’** must replace **‘best interest’ determinations**

# Over-protection 1: The MCA and the UNCRPD

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- **The considered view is that the MCA is non-compliant with the UNCRPD**
- **There are a number of concerns, however with ensuring compliance**
  - Mental capacity is taken to be largely congruent with the capacity for autonomous decision-making. But... what precise status does 'will and preferences' have when a person is not able to exercise her autonomy?
  - The 'will and preferences paradigm' presupposes an ideal of independent choosers – unable to handle situations where abuse, manipulation, coercion or exploitation is present (Kong, 2015)
- **A number of legal strategies proposed to improve compliance**
  - Over-weighting of current wishes and preferences' in best interests determinations (Essex Autonomy Project, 2017)
  - Full embrace of supported decision-making frameworks (Richardson, 2012)

# Over-protection 2: End of life care and the legitimacy of extra safeguards

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- The MCA introduces extra safeguards where court applications need to be made before a decision is made (even when there is unanimous consensus that the decision would be in the person's best interests)
- These include:
  - the proposed withdrawing of ANH from a patient in PVS
  - Tissue or organ donation
  - Non-therapeutic sterilization
- Concern raised that these safeguards are to the detriment to the person's best interests, particularly in relation to end of life care decision-making – where timely action will prevent harm

# Over-protection 2: End of life care and the legitimacy of extra safeguards

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- ***An NHS Trust v Y (2017)***: Is it mandatory to bring to court the withdrawal of ANH from a patient with a prolonged disorder of consciousness – when there is full agreement about best interests?
- The High Court decision: no legal obligation to hear these cases if good medical practice has been followed. This judgement is currently being appealed in the Supreme Court.
- Human rights law drawn upon to challenge the High Court's decision:
  - Withdrawal of ANH engages Mr Y's Article 2 and 6 rights
  - The Court of Protection offers an appropriate safeguard to protect these rights by ensuring Mr Y's voice is heard

# Concluding remarks

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- **The MCA sits in an uneasy relationship with human rights law**
- From some legal angles, the MCA is seen to inappropriately limit justifiable protection interventions. From other legal angles, the MCA is seen to unjustifiably discriminate against people with disabilities
- The DoLS and Y case also point towards circumstances in which formal processes instigated to safeguard human rights protections might actually function to act against the interests of the person
- **Expect major changes to DoLS, and more minor amendments to the MCA – including a brand new Code of Practice coming soon**
  - The debate about MCA and CRPD compliance is likely to rumble on...

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Thank you

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