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Eating Disorders, Autonomy and Capacity | Healthcare and Serious Medical Treatment Team Launch Event

doughty street chambers

Tuesday 29th November 2022

SPEAKERS

- **Sophy Miles**, Doughty Street Chambers (barrister specialising in Mental Capacity Law and head of the Court of Protection and Mental Health Team)
- **Dr Nikola Kern**, Consultant Psychiatrist (South London and Maudsley NHS Foundation Trust)
- **Ulele Burnham**, Doughty Street Chambers (barrister specialising in Mental Capacity Law and head of the Court of Protection and Mental Health Team)
- **Leonie Hirst**, Doughty Street Chambers (barrister specialising in Mental Capacity Law and a member of the Court of Protection and Mental Health Team)
- **Professor Beverley Clough**, Associate Professor of Law and Social Justice at Leeds University (soon to be Chair of Law at MMU)

Sophy Miles

Mental Health and Court of Protection Team
Doughty Street Chambers

Autonomy & Capacity in Eating Disorders

Dr Nikola Kern
South London & Maudsley NHS Foundation Trust

Talk map

- Historical Context, Diagnoses
- Aetiology, Epidemiology, Course of disease
- Psychodynamic understanding of AN
- Complexities of capacity assessments & interplay with MHA including some examples

Historical context

Image: Picture of Sir William Gull

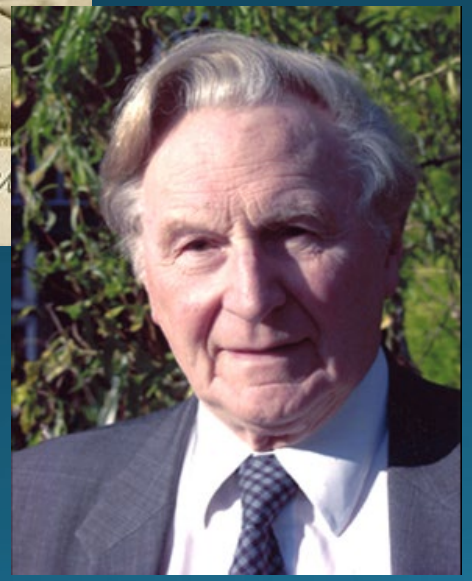


Image: Picture of Prof Gerald Russell

- **Sir William Gull**
  & **Charles Lasègue**
  Anorexia nervosa 1873

- **Professor Gerald Russell**
  Bulimia Nervosa 1979

- BN was included with AN in the 1980 DSM-III
- BED & ARFID were introduced as a separate disorders in the 2013 DSM-5

Diagnostic Categories Increased DSM 5 & ICD 11 aligned

- 6C00 Anorexia Nervosa (1873)
- 6C01 Bulimia Nervosa (1979)
- 6C02 Binge Eating Disorder (DSM 5)
- 6C03 Avoidant-Restrictive Food Intake Disorder (DSM 5)*
- 6C04 Pica (DSM 5)*
- 6C05 Rumination-Regurgitation Disorder (DSM 5)*
- 6C0Y Other Feeding and Eating Disorder (DSM 5)

* Previously in childhood feeding disorders

- *Feeding and Eating Disorders ICD 11 World Health Organization. International statistical classification of diseases and related health problems, 11th revision (ICD-11).*

In ICD-11 subjective & objective loss of control of eating =binge

Anorexia Nervosa (DSM-5)

A. Restriction of energy intake relative to requirements, leading to a significantly low body weight in the context of age, sex, developmental trajectory, and physical health (typically this would include BMI <18.5).

B. Intense fear of gaining weight or becoming fat, or persistent behaviour that interferes with weight gain, even though at a significantly low weight.

C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or persistent lack of recognition of the seriousness of the current low body weight.

Specify type – restricting or binge-eating /purging
(during the last 3 months)

Bulimia Nervosa (DSM-5)

A. Recurrent episodes of binge eating. An episode of binge eating is characterized by both of the following:
   1) Eating, in a discrete period of time (e.g., within any 2 hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances.
   2) A sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating).

B. Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as self-induced vomiting; misuse of laxatives, diuretics, or other medications; fasting; or excessive exercise.

C. The binge eating and inappropriate compensatory behaviours both occur, on average, at least once a week for 3 months.

D. Self-evaluation is unduly influenced by body shape and weight.

E. The disturbance does not occur exclusively during episodes of AN.

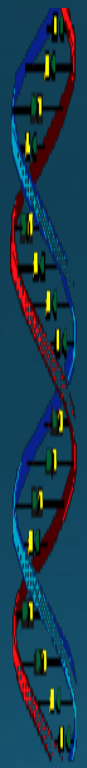
How common are eating disorders?

- There is a lot of variation because studies have varied in which EDs are assessed (i.e., AN and BN vs. the full spectrum)

- 6% has been identified as a conservative but inclusive point prevalence estimate for all DSM-5 disorders, in both sexes across the adult years
  - For AN, ≈0.5%
  - For BN, ≈1%
  - For BED, ≈3%

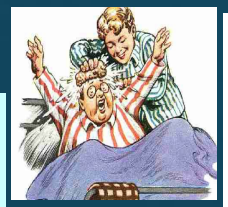
- Rates of BN increased over the 1990's but may now have stabilised
- Slow surge for BED, BN and OSFED over pandemic
- Rates of AN are more stable but mean age of onset has reduced and significant increase during pandemic

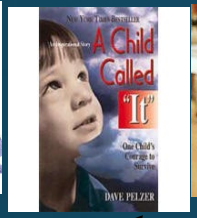
Predisposing Risk Factors



ADHD

Insulin resistance BMI↑



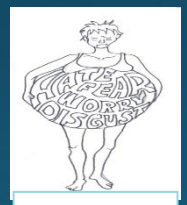


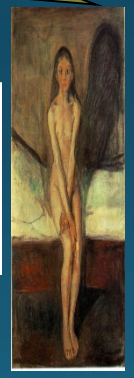
Bulimia Nervosa BED

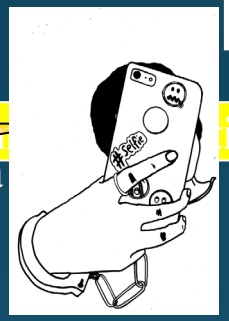
Substance Abuse Depression

0 Genes and Environment ion 20

STRESS, Loneliness, weight stigma







Anorexia Nervosa

Severe enduring AN (SEED) Depression

OCD ↑
BMI↓
Insulin sensitivity

Jacobi 2003, Stice 2002, Treasure et al 2020

Precipitating factors

- Life events & difficulties
- Negative affect/ depression
- Social difficulties (general & weight related)
- Weight loss
- Dieting
- Comments about / focus on eating/weight/shape

Perpetuating Factors

- Biological factors related to eating disorder symptoms (starvation effects, brain reward systems, neurobiological habit formation)
- Social factors (interpersonal conflict, social withdrawal, loneliness)
- Difficult emotions
- Weight comments / stigma
- Diet culture (social media)
- Responses from close others
- Addictive factors, habit

The course of Eating Disorders

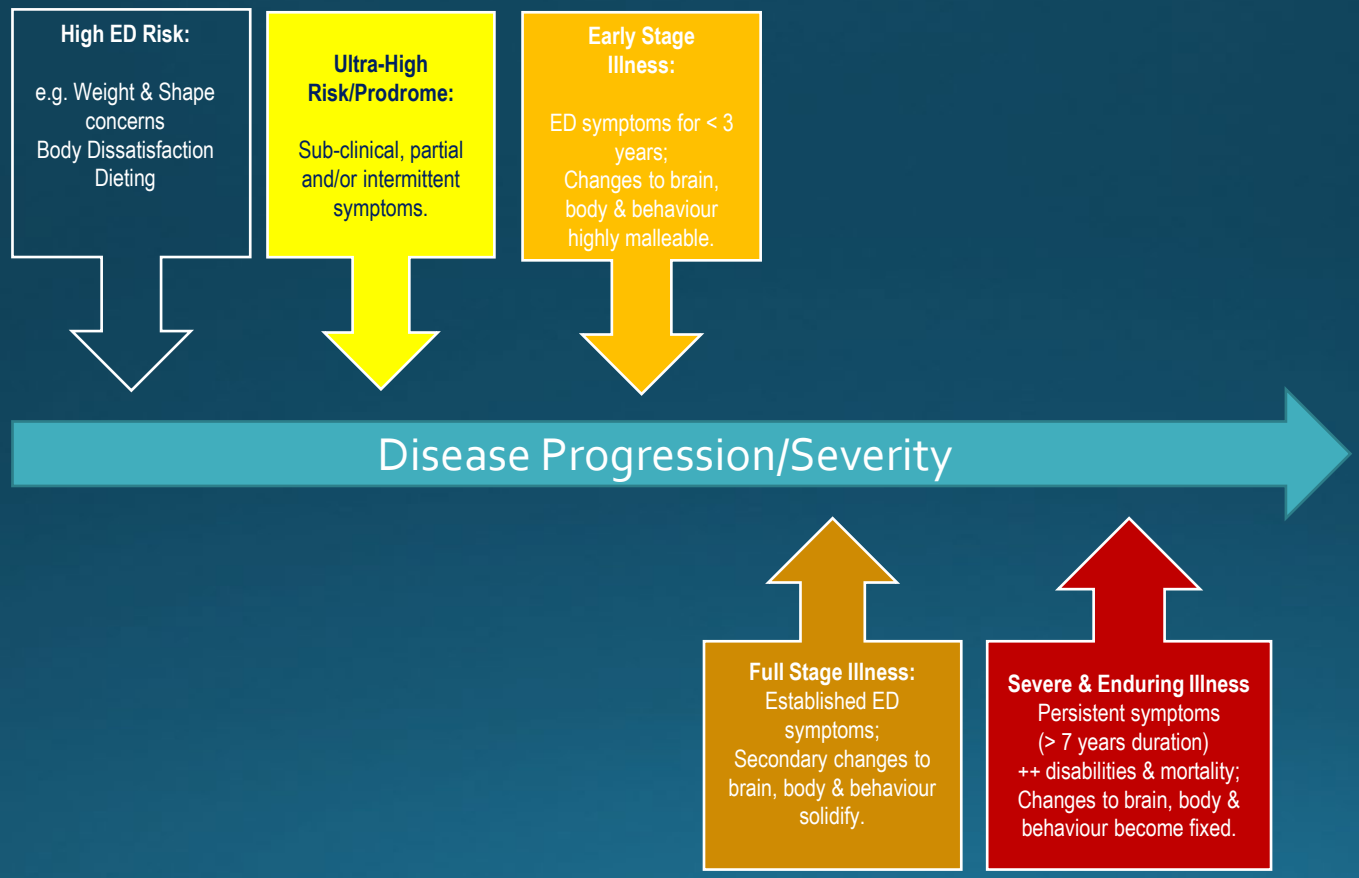
- Majority onset adolescence and young adulthood
- Many cases continue for decades
- Many cases will change from one diagnostic status to another, from restrictive Anorexia Nervosa to binge/purge AN, Bulimia Nervosa, Binge Eating Disorder

Prognosis

- Illness duration is a key predictor of treatment outcomes; best with duration of illness < 3 years.
- Eating disorders are associated with significant structural and functional brain changes – reversible with weight restoration (?)
- Eating disorder behaviours are initially rewarding, then habitual, then neurocognitively engrained
- Eating disorders typically develop in adolescence and young adulthood, when the brain is still developing -potential to disrupt brain maturation.
- AN highest psychiatric mortality rate (5-20%)
- Longer duration associated with poorer prognosis, but recovery remains possible (20% of patients develop enduring AN)
- Treatment goals might be shifting to living with some meaning rather than weight recover

Nielsen et al1998; Walton et al 2022; Fonville et al 2014; Kaufman et al 2020; Fichter 2017; Murray 2019

Stage Model of Illness



J Clin Psychiatry. 2017 February ; 78(2): 184–189. doi:10.4088/JCP.15m10393.

Recovery From Anorexia Nervosa and Bulimia Nervosa at 22-Year Follow-Up

Kamryn T. Eddy, PhD[a,b,*], Nassim Tabri, PhD[a,b], Jennifer J. Thomas, PhD[a,b], Helen B. Murray, BA[a], Aparna Keshaviah, MSc[a], Elizabeth Hastings, BA[a], Katherine Edkins, BA[a], Meera Krishna, BA[a], David B. Herzog, MD[b], Pamela K. Keel, PhD[c], Debra L. Franko, PhD[a,d]

At 22-year follow-up:

- 62.8% of participants with anorexia nervosa recovered
- Approximately half of those who had not recovered by 9 years were recovered at 22 years.

Psychodynamic Understanding of ED

- Border conflict between inside and outside
- To say No is to say I – boundaries of the self
- Denial of hunger/longing/dependence
- Defense against overwhelmingly strong hunger/longing for the other-threat to identity
- Hunger to be recognised for one's own self versus
- Existential shame about neediness and dependence
- Conflict around separation/individuation
- Being thin: visible sign of separatedness and strength
- Repetition compulsion

Capacity assessment
Authentic wish versus decision driven by ED

- Difficulties related to intellectual functioning subtle
- Shift in value system "rather be dead than gain weight"
- Strong identification with the disorder in AN, i.e. part of the self
- ED as a way of coping, driving force-existential threat to be without it
- BN – strong dissonance between their first & second order desires (shame)
- Difficulty making decisions that could "betray" the eating disorder
- Difficulty appreciating the seriousness , i.e. "not sick enough"
- Belief of not being worthy of help, a burden
- Comorbidities i.e. OCD, depression, anxiety, ASD, EUPD
- Developmental regression/delay/missing out – no sense of a premorbid adult self, recovery as existential threat

Craigie 2011; Tan et al 2007 ; Tan et al 2013

Compulsory treatment

- Evidence for efficacy of compulsive treatment is equivocal
- Patients & families generally agree (in hindsight) that this can be necessary to save life
- Liberitarian position versus utilitarian/paternalistic position hinges on medical risk and appropriateness of treatment
- Sometimes counterproductive to override patient's choice, i.e impractical or unsafe, re-enacting past experience of abuse, not least restrictive
- Patients might be relieved if others take decisions (not betraying AN),i.e. negligent not to enforce treatment
- Not whether but when we let people refuse treatment or perhaps who?
- Working with ambivalence
- Need to understand each patient's unique position and to adapt our approach & goals to minimise suffering

Atti et al 2021; Ramsay et al 1999;Tan et al 2010, Guarda et al 2007

Things to consider in practice

- Countertransference, self-awareness, i.e. heroically saving someone, alleviate own distress, gaining sense of control
- defensive practise in the face of zero death campaigns, fear of persecution/being sued by courts
- Status/outcome focused capacity assessments
- Use of "leverage" – patients approve but not "best practise"
- Need to understand each patient's unique position and to adapt our approach & goals to minimise suffering
- MCA offers a framework for this, include MHA into best interest process

Tan et al 2010

EATING DISORDERS AND AUTONOMY

Serious Medical Treatment Seminar

Mental Health and Court of Protection Team
Doughty Street Chambers

29 November 2022

Ulele Burnham

Anorexia Nervosa

Re W (medical treatment: anorexia) [2016] EWCOP 13 at [1]

‘ (from the Greek an-/without -orexia/appetite) is a pernicious condition. In its **severe form it is life-governing and potentially fatal…..**The normal energy intake for an adult woman is about 2000 calories a day. A healthy Body Mass Index (‘BMI’) is between 18.5 and 25. If the body uses more energy than it gains over a prolonged period, the result is malnutrition, with a global effect on wellbeing. The physical consequences can include endocrine disorder preventing the onset of puberty, slow heart rate, low blood pressure, hypothermia, anaemia, reduction in white blood cells, reduction in bone density and reduced immune system functioning….

How does the case law define Eating Disorders?

Re W (medical treatment: anorexia) [2016] EWCOP 13 at [1]

The social consequences for individuals and their families can be devastating, as they damage or destroy normal social development. The psychological consequences for the sufferer include a mental life dominated by thoughts of food. The act of eating is all too easy for most people in developed societies. But for the sufferer, whose life would be utterly transformed by the most modest food consumption, the ability to eat is seemingly overpowered. Years are spent thinking and talking about eating, but talking about eating is not the same thing as eating.' (Paragraph [1].)

A local authority v E & ors [2012] COPLR 441 at [26]

"…a pervasive psychiatric illness in which the sufferer has a grossly distorted perception of her correct body shape. Cardinal features are a morbid fear of weight gain, with behaviour aimed at weight loss, and amenorrhea…"

How does the case law define Eating Disorders?

Anorexia:

involves "profound and illogical fear of weight gain"
(**Northamptonshire Healthcare NHS Foundation Trust v AB [2020] EWCOP 40 at [32]**)

"extreme aversion to adequate nutrition…an over evaluation that being low weight is desirable and that being considered fat is so aversive it is to be avoided at all costs. The avoidance of this becomes extreme and out of proportion to biological norms.

The weight that [ ] places on the desire to be thin and avoidance of being fat is therefore out of proportion to the situation and she palaces undue weight on the need to achieve this goal In my opinion this undue weighting on the need to be thin above all else is what sets [AB's] decision-making ability apart from that of someone who has capacity." [50]

How does the case law define Eating Disorders?

Bulimia Nervosa DSM-5 307.51(F50.2)

- Recurrent episodes of binge eating.

- Recurrent inappropriate compensatory behaviours to prevent weight gain.

- Self-evaluation that is unduly influenced by body shape and weight.

Capacity and E[illegible]ers

General Principle:

"…a person cannot be considered to be unable to use and weigh information simply on the basis that **h**e or she has **applied his or her own values or outlook to that information in making the decision in question and chosen to attach no weight to that information in the decision-making process."**

(Kings College Hospital NHS Foundation Trust v C [2016] COPLR 50 at [38])

Eating disorder cases:

The finding of a lack of capacity rests upon the very application of individual values to an extent considered "overvalued".

Principle of avoiding a finding of lack of capacity simply because of an application of eccentric values strained in most eating disorder cases.

Capacity and Eating Disorders (1)

- Uniquely, decided cases concern decision-making about treatment for very impairment said to cause compromised decision-making.

- Upshot is that an unwise decision is highly likely to be regarded as pathological

➔ *Anorexia interferes with the ability to accept sufficient nutrition*

➔ *This interferes with the ability to make reasoned decisions about treatment (e.g. tube feeding)*

➔ *Although able to understand, retain and communicate, the decision is not capacitous because anorexic cognitions affect the ability to use and weigh the information*

[Northamptonshire Healthcare NHS Foundation Trust v AB at [56]

"obsessive fear of weight gain…incapable of weighing the advantages and disadvantages of eating in any meaningful way" **A local authority v E & ors [2012] COPLR 441 at [49]**

Capacity and Eating Disorders (2)

- Survey of cases indicates that an inability to "use and weigh" is what tends to vitiate capacity in ED sufferers:

  lack of insight into seriousness of condition (lack of correspondence between risk and perception of risk)

  'anorexic cognitions" drive decisions.

  "her ability to weigh the decision in the balance is significantly disturbed by her fear of weight gain."

  judgment "critically impaired by a profound and illogical fear of weight gain."

  - only one case in which P was found to have capacity to make decision to refuse treatment: **Lancashire and South Cumbria NHS Foundation Trust v Q & ors [2022] COPLR 315**

Academic Literature:

➔ Many eating disorder sufferers remain reasonably intellectually unimpaired but are "impaired in their ability to make decisions with respect to the treatment of their own eating disorder…through a range of mechanisms unrelated to intellectual functioning"

➔ "Anorexia..is a philosophically fascinating disorder because it incorporates a particular value or an overly strong value, as one of its criteria – in other words, a pathological, or pathologically strong, value. The legal and standard ethical understandings of capacity studiously avoid any mention of values. This perfectly understandable particularly in the light of the history of psychiatry as it is crucial that definitions are not open to abuse by majorities who wish to condemn those with minority or alternative value systems as somehow incapacitated. Yet this avoidance misses the point for disorders like anorexia nervosa where a strongly held value is core to the disorder itself"

(Tan & Richards, *Legal and Ethical Issues in the Treatment of Really Sick Patients with Anorexia Nervosa"*, Robins & Nicholls (Eds) **Critical Care for Anorexia Nervosa**, Springer, Switzerland 2015)

➔ Are eating disorders always driven by "compulsive psychological force that precludes the exercise of genuine decision-making"?

➔ Can food refusal be a "strategy for asserting and maintain a limited domain of self – determination" in the context of trauma and personal loss? Cases allude to an aspect of behaviour being directed at control but do not offer than as prism through which decision-making can be evaluated.

➔ Is there a conflict between the *Aintree* (and CRPD) standard of giving respect to the *values* that inform the refusal of food; i.e. "not presupposing that these coincide with the values that motivated the offer" and a determination that food refusal is pathological? What are the values of the particular ED sufferer ?

➔ If AN is by nature a disorder of over-valued ideas what are the circumstances in which competence is retained?

See *Human Rights and Human Experience in Eating Disorders,* Martin W, Journal of Psychosocial Studies, Special Issue, Vol. 10, Issue 2, October 2017.

➔ Absence of <u>any</u> cases in which any person suffering from Anorexia Nervosa was found to have capacity to make relevant treatment decisions.

➔ Notably, one case in which the person concerned was found to have the capacity to refuse recommended treatment, the eating disorder was Bulimia (**Lancashire and South Cumbria NHS Foundation Trust v Q & ors [2022] COPLR 315)**

- The treatment proposed was <u>not</u> treatment for the bulimia itself but for hypokalemia (condition of lower than normal potassium levels)

-Q: "The value an individual attributes to life may correlate with their experience of it or their perception of its quality….To my mind that does not automatically establish an inability to weigh life and death in the balance. On the contrary, it may represent a finely calibrated utilitarian calculation" Q at [45]

Acknowledgment by the court of the peculiarity of cases re AN in E:

E's parents recorded as having said:

"It seems strange to us that the only people who don't seen to have the right to die when there is no further appropriate treatment available are those with an eating disorder. This is based on the assumption that they can never have capacity around any issues connected with food. There is a logic to this, but not from the perspective of the sufferer who is not extended the same rights as any other person" [52]

Jackson J (As he then was):

"I acknowledge that a person with severe anorexia may be in a Catch 22 situation regarding capacity: namely, that by deciding not to eat, she proves that she lacks capacity to decide at all" [53]

A local Authority v E and ors [2012] EWHC 1639 (COP):
"decisions about her treatment"

The NHS Trust v L & ors [2013] COPLR 139 :
"capacity to make decision in relation to serious medical treatment and in particular nutrition and hydration and the administration of dextrose for hypoglycaemic episodes."

A NHS Foundation Trust v Ms. X [2015] COPLR 11:
"capacity to…make decisions in relation to the subject matter in issue (i.e. the treatment decisions in relation to anorexia)"

What is the decision subject to scrutiny?

Cheshire and Wirral Partnership NHS Trust v Z [2016] EWCOP 56:
"capacity…to make decisions as to whether to undergo treatment for her anorexia including whether to accept or refuse feeding by nasogastric tube."

Re W (medical treatment: anorexia) [2016] EWCOP 13
"capacity to make decisions about the care and treatment of the condition [AN]"

ER [2021] COPLR 353:
"capacity to make decisions about hospital admission and treatment for anorexia"

Northamptonshire Healthcare NHS Foundation TRIST V AB [2020] EWCOP 40
"capacity to decide whether or not to be tube fed."

➔ Court increasingly inclined to identify decision precisely > autonomy

Eating Disorders and Best interest decisions

Strong presumption that all steps will be taken to preserve life (*Bland*) not absolute. Can be departed form where treatment is "futile, overly burdensome to the patient or where there is no prospect of recovery" .

In majority of cases concerning severe anorexia, forced-feeding/detention under the MHA *was neither proposed nor found to be* in the best interests of P.

Only one case – E – in which treatment imposed against P's will.

Eating Disorders and Best interest decisions (1)

Relevant factors:

- prospect of engagement with psychological treatments to address eating disorder.

- extent of distress or trauma likely to be caused

- life expectancy and co-morbidity.

– whether treatment proposed carries risk of serious injury/death itself: **L[2013] COPLR 139** ➔ experts could find no reports of patients with BMI as low as L surviving enforced feeding; sedation could cause iatrogenic death

-whether enforced feeding in breach of Arts 3/8 **(X [2015] COPLR 11**

ADVANCE DECISIONS AND LITIGATION CAPACITY: ISSUES ARISING IN ED CASES

LEONIE HIRST
BARRISTER AT DOUGHTY STREET CHAMBERS

ADVANCE DECISIONS

ADVANCE DECISIONS: THE FRAMEWORK

- s24 MCA 2005: defines 'advance decision'
  - Decision by adult with capacity to do so that at later time, and in specified circumstances where P has lost capacity to consent, a specified treatment is not to be carried out or continued

- S5 Mental Capacity Act 2005: Acts in connection with care or treatment
  - Protects D from liability where D does an act in connection with care or treatment, where D takes reasonable steps to establish whether P has capacity and reasonably believes the act is in P's best interests
  - The effect of a valid and applicable advance decision is to disapply s5

- ss 24-25 MCA 2005: were intended to "codify and clarify" existing common law
  - Principle of autonomy: a capacitous individual can refuse any treatment including life-sustaining treatment
  - Temporal lag between AD and operation of AD gives rise to potential tension with concept of 'informed consent' which is central to common law autonomy/negligence
  - AD does not give a positive right to choose or direct a particular course of treatment, but request/preference in 'advance statement' should be taken into account by treating doctor: cf Code of Practice

ADVANCE DECISIONS: CONTENT

- No formal structure or template in Act

- Must be in writing, signed by P or at P's direction, and witnessed (importance of compliance with procedural requirements emphasised in *NHS Cumbria CCG v Rushton* [2018] EWCOP 41 and *W v M* [2012] COPLR 222) but may be withdrawn or altered verbally

- Decision should have 'core features' identified in *Rushton* (reflected in Code of Practice):
  - Full details of P
  - Name and address of P's GP, and whether he/she has copy of the AD
  - A statement that the decision should be used if P ever lacks capacity to make treatment decisions
  - A clear statement of the decision, the treatment to be refused and the circumstances in which the AD will apply
  - The date of the AD
  - P's signature
  - Signature of witness

- Failure to comply with procedural requirements, especially signature and witness, will invalidate AD; but can still be used as evidence of P's wishes and feelings

VALIDITY AND APPLICABILITY

- To operate, an advance decision must be both valid and applicable to the treatment in question
- Decision not valid if P lacked capacity to make it at the time it was made: this is often the key issue
- Decision not valid if procedural requirements in s24/25 MCA not complied with
- S25 MCA 2005: Decision is not valid if:
  - P has withdrawn it
  - P has conferred authority on donee of LPA to give or refuse consent to treatment
  - P "has done anything else clearly inconsistent with the advance decision remaining his fixed decision"
- S25 MCA 2005: Decision is not applicable to the treatment if:
  - It is not the treatment specified in the decision
  - The circumstances specified in the decision are absent
  - There are "reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them"
  - Not applicable to life-sustaining treatment unless the decision is verified by a statement by P that the decision should apply to that treatment even if P's life is at risk

ADVANCE DECISIONS: CAPACITY ISSUES

- No requirement for assessment of capacity to make AD at the time it is made

- Can lead to problems at point at which AD becomes operational, especially where 'wisdom' of decision to refuse treatment is questioned (presumption of capacity vs 'unwise' decision)

- Difficulties in assessing historic capacity, especially where AD was made a long time ago
  - Need for 'clear evidence' of capacity at the relevant time, especially where AD concerns life-sustaining treatment
  - AD will not be upheld where evidence of capacity is "doubtful or equivocal"
  - *A Local Authority v E* [2012] EWCOP 1639: AD refusing resuscitation or any medical intervention was invalid where no formal capacity assessment carried out, in circumstances where there was reason to doubt E's capacity (anorexic inpatient under MHA 1983)

- In eating disorder cases, nature of P's diagnosis may affect whether P can ever have capacity to make an AD, especially to refuse artificial feeding/hydration: cf *E* ("*I acknowledge that a person with severe anorexia may be in a Catch 22 situation regarding capacity: namely, that by deciding not to eat, she proves that she lacks capacity to decide at all*")

ASSESSING CAPACITY FOR AN AD: ISSUES

- Ability/inability to make a decision is distinct from the decision which P may or may not make
  - *S v Birmingham Women's and Children's NHS Trust* [2022] EWCOP 10: "*I am conscious that S may not yet have reached a final decision as to whether she wishes to terminate her pregnancy or not… It is not necessary that she is "sure" of what her decision will be for her to retain capacity to make the decision.*"

- The nature of the decision: refusal of treatment (even life-sustaining treatment) is distinct to a decision or desire to die
  - "*Q does not want to die, but she does not want to live under a medical and mental health regime which she finds oppressive and corrosive of her autonomy*"

- The need not to "*allow the tail of welfare to wag the dog of capacity*" (*Heart of England NHS Foundation Trust v JB* [2014] EWCOP 342 – described by Hayden P in *Q* as "*an ever-present danger for all the professionals involved in these cases including, if I may say so, the Judge*"

- The nature of the 'relevant information' and whether available to P at time AD made:
  - 'relevant information' may not have been available to P when AD was made for variety of reasons (including medical advances, changes in nature of P's condition and treatment)
  - Includes 'consequences of making or not making the decision', so P's past experience of treatment and quality of life with or without treatment highly relevant

WHAT IS THE 'TREATMENT'?

- How is 'treatment' defined?
  - S64 MCA 2005 not particularly helpful: "'treatment' includes a diagnostic or other procedure"
  - S5 MCA 2005 distinguishes between 'care' and 'treatment' (cf Code of Practice) but does not define either
  - Treatment can include provision of nutrition and hydration 'via medical procedure' to a patient who is unable to feed himself: *Airedale NHS Trust v Bland* [1993] UKHL 7 (artificial feeding of patient in persistent vegetative state through nasogastric tube)
  - May need medical evidence as to whether particular process is 'treatment': how far does *Bland* extend?

- Treatment must be specified with sufficient clarity in AD: *W Healthcare NHS Trust v H* [2004] EWCA Civ 1324 ("*being kept alive by machines*" not sufficiently clear to amount to decision to refuse artificial nutrition/hydration)

TREATMENT FOR MULTIPLE CONDITIONS

- *NHS Foundation Trust v Ms X* [2014] EWCOP 35
  - X had anorexia and alcohol dependence disorder: assessed as having capacity to make decisions about drinking, but not to make decisions about her eating disorder. Court therefore only had jurisdiction in relation to treatment for anorexia
  - X's alcohol dependence had caused serious and irreversible liver disease: X made AD in relation to liver disease, refusing admission to hospital, CPR, or calling an ambulance. AD not operational because X retained capacity in respect of treatment for liver disease
  - Court careful to make a distinction between the two conditions, and X's AD taken into account in considering her wishes and feelings in regards to treatment for anorexia
  - Declaration that it was in X's best interests not to receive treatment for anorexia

MENTAL HEALTH TREATMENT

- S28 MCA 2005: Advance decision can be overridden where P is receiving "treatment for mental disorder" regulated by Part IV Mental Health Act 1983.
  - Includes most but not all patients liable to detention under MHA, Community patients recalled under s17E
  - Does not include electro-convulsive therapy
  - Where applicable, 'treatment' has same meaning as s145 MHA 1983: includes nursing, psychological intervention, specialist rehabilitation and care

- Treatment for mental disorder or treatment for physical consequences? *Lancashire & S Cumbria NHS Foundation Trust v Q* [2022] EWCOP 6
  - Q had been detained under s3 MHA 1983 to ensure compliance with potassium injections including the use of restraint. Q discharged under CTO, with conditions requiring her to attend appointments, 'engage constructively' with health professionals in the 'management of consequences of her ED', which included regular blood tests and hospital admissions. Q had complied with treatment, but "under duress" of threat of recall
  - Q's AD refused "*all treatment relating to low electrolytes, orally, intravenously regardless of my physical condition*" including resuscitation, ICU etc: "*in short, no physical interventions to treat the consequences of chronic bulimia*"
  - Prospect of recall under MHA being used to override AD
  - AD upheld as valid

LITIGATION CAPACITY

LITIGATION CAPACITY

- The test: *Masterman-Lister v Brutton & Co* [2002] EWCA Civ 1889 and *Dunhill v Burgin* [2012] EWCA Civ 397
  - "…whether the party…is capable of understanding, with the assistance of such proper explanation from legal advisors and experts in other disciplines as the case may require, the issues on which their consent or decision is likely to be necessary in the course of those proceedings"
  - "whether a party…is capable of instructing a legal advisor with sufficient clarity to enable P to understand the problem and to advise her appropriately"; P should be able to "understand and make decisions based upon, or otherwise give effect to, such advice as she may receive"

- Statutory principles: s1 Mental Capacity Act 2005
  - Presumption of capacity unless lack of capacity "established": s1(2)
  - The requirement for 'all practicable steps' to help P make a relevant decision

LITIGATION CAPACITY V SUBJECT CAPACITY

- The 'traditional' view: rare for P to lack subject-matter capacity but to have litigation capacity
  - *Sheffield City Council v E* [2004] EWHC 2808: Lack of subject matter capacity implies lack of litigation capacity given that decisions are closely related. Only in 'unusual circumstances' would someone lacking subject-matter capacity have litigation capacity
  - *S v Birmingham Women's and Children's NHS Trust* [2022] EWCOP 10: "*it would be very unusual for a person to have capacity to litigate proceedings but lack capacity to decide the issue which was the object of those proceedings*" (S deemed to have subject matter capacity so issue not revisited by the court)
  - More extreme expression by Mostyn J in *An NHS Trust v P* [2021] EWCOP 27: conducting proceedings is "*a dynamic transactional exercise requiring continuous, shifting, reactive value judgments and strategic forensic decisions*". "*I would go further and say that it is virtually impossible to conceive of circumstances where someone lacks capacity to make a decision about medical treatment, but yet has capacity to make decisions about the manifold steps or stances needed to be addressed in litigation about that very same subject matter…*" – "*as rare as a white leopard*"

LITIGATION CAPACITY V SUBJECT CAPACITY

More balanced approach by Hayden P in *Re Q*

- Although an individual will frequently lack capacity to litigate where she lacks capacity to decide about medical treatment, the two tests should not be regarded as synonymous: *Masterman-Lister* remains the test
- "*Observations of Mostyn J in P have been afforded greater weight than I am sure he would have intended*"

Is split between litigation capacity and subject matter capacity more likely in ED cases due to nature of diagnosis?

In practice, although there are cases where P has been accepted to have litigation capacity, there do not appear to have been any ED cases where litigation capacity is contested and P has been deemed not to have subject matter capacity but to have litigation capacity

ASSESSING LITIGATION CAPACITY

- Principles in *AMDC v AG & CI* [2020] EWCOP 58 apply:
  - Expert report on capacity is not a clinical assessment
  - The requirement for 'all practicable steps' to help P make a relevant decision

Official Solicitor guidance notes on litigation capacity certificate go further: matters to be considered include understanding of how the proceedings are funded; the risk of an adverse costs order; capacity to give proper instructions for and approve the particulars of claim; to approve a compromise

Must be assessed/determined in context of the particular proceedings: *Sheffield City Council v E* [2005] Fam 236

Need to ensure that litigation capacity is distinguished from the course of action which P is pursuing in litigation: cf *Re Q ("The guiding principle here, as always, is the importance of distinguishing an 'unwise decision' from one upon which P lacks capacity"*)

Who is appropriate assessor?

- Psychiatrist/clinician v legal representatives
- In practice, court likely to accept views of 'experienced' legal representatives, especially where supported by witness evidence: *Re S, Re Q*

Anorexia and compulsory treatment: The role and potential of law

BEVERLEY CLOUGH
LEEDS/MMU

Overview

- Briefly reflect on role of MHA and MCA
- Critical reflections from
  - Therapeutic jurisprudence
  - Feminist bioethics

- The UNCRPD: going beyond capacity

Mental Health Act

- s63 treatment for the mental disorder
- capacity not relevant
- seen as more coercive and less protective of autonomy

Mental Capacity Act

- Capacity assessment
- Best interests?
- 2 key issues driving this area
    - Every CoP case involving anorexia- found to lack mental capacity
    - Every case has had the same medical expert [Why is this?]

Therapeutic Jurisprudence?

- what impact does the use of the law have in terms of therapeutic and psychological impact on the individual?
- not necessarily about the clinical impact of the treatment decision, but about the role of law- empowerment, control etc..

> **“This theoretical frame might be relevant at several points where law ‘brokers’ the use of coercion in the management of severe anorexia nervosa. These points are located where the law leaves a ‘decisional space’ in which choice or flexibility might be exercised.” (Carney and Saunders, 2003)**
>
> Carney, Terry and Dominique Saunders. “Therapeutic Jurisprudence and Anorexia: A Synergy?” Law in context 20 (2003): 54.

Insights for anorexia and law

- MHA more coercive?
- Yet, need to be cautious in making too broad conclusions here.
- when do/should legal intervention occur?

Trends in case law- handing back control to individuals?

- Ms X- *I understand the professionals concerns and the effect that this has had on all of them and I do recognise that everyone wants for the best. However … rather than helping me, it is actually making me worse … but I am also fully aware that there is support and treatment still available if I ever want it.*
- Re Z

Feminist Bioethics

Kirsty Keywood, 2000

"all cases to come before the courts have concerned female anorexics. This is perhaps not surprising, given that approximately 90 percent of those physically diminished by the condition are women (Bowers and Andersen, 1994: 193). An examination of the role that gender plays in the courts' constitution of the anorexic subject will tell us something **about law's engagement with female embodiment more generally, for the legal disciplining of the anorexic female body forms part of a broader deployment of practices which constitute and discipline the female body in law**. While the courts are not explicit on the role that gender plays in their decisions, the **anorexia case law highlights uneasy parallels with dominant medical and philosophical discourses, both of which have operated in various contexts to render female corporeality in need of clinical regulation and moral management**."

Keywood, K. (2000). My Body and Other Stories: Anorexia Nervosa and the Legal Politics of Embodiment. Social & Legal Studies, 9(4), 495–513. https://doi.org/10.1177/096466390000900402

Feminist Bioethics

- Broader context of medico-legal framework and medical dominance within this
  - How is it maintained?
    - Always lack mental capacity
    - Catch-22
    - Re AB

- Impoverished view of autonomy in medical law
  - Medicalises anorexia/ overlooks socio-cultural and historical aspects (Bordo, 1992; Keywood, 2000)
  - Decontextualises experiences and realities of choice
  - Resources?- see B. Clough Anorexia, Capacity, and Best Interests: Developments in the Court of Protection Since the Mental Capacity Act 2005. Med Law Rev. 2016 Summer;24(3):434-445. doi: 10.1093/medlaw/fww037

UNCRPD

- Article 12
-Para 42 General Comment No 1

- … forced treatment by psychiatric and other health and medical professionals is a violation of the right to equal recognition before the law and an infringement of the rights to personal integrity (art. 17); freedom from torture (art. 15); and freedom from violence, exploitation and abuse (art. 16). This practice denies the legal capacity of a person to choose medical treatment and is therefore a violation of article 12 of the Convention**. States parties must, instead, respect the legal capacity of persons with disabilities to make decisions at all times, including in crisis situations; must ensure that accurate and accessible information is provided about service options and that non-medical approaches are made available; and must provide access to independent support. States parties have an obligation to provide access to support for decisions regarding psychiatric and other medical treatment.** Forced treatment is a particular problem for persons with psychosocial, intellectual and other cognitive disabilities. **States parties must abolish policies and legislative provisions that allow or perpetrate forced treatment, as it is an ongoing violation found in mental health laws across the globe, despite empirical evidence indicating its lack of effectiveness and the views of people using mental health systems who have experienced deep pain and trauma as a result of forced treatment**. The Committee recommends that States parties ensure that decisions relating to a person's physical or mental integrity can only be taken with the free and informed consent of the person concerned.

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Q + A

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