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SEVERE AND ENDURING ANOREXIA NERVOSA IN THE COURT OF PROTECTION IN ENGLAND AND WALES

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ABSTRACT

This article explores legal issues relating to the continuation of in-patient treatment for people with severe and enduring Anorexia Nervosa in circumstances where there are doubts as to treatment efficacy. In five recent cases, the Court of Protection in England and Wales has been asked to consider the capacity and best interests of patients with severe and enduring Anorexia Nervosa. Drawing upon international comparisons, this article outlines the clinical uncertainties associated with prognosis and treatment and evaluates legal assertions surrounding capacity and best interests. It is suggested that to ensure palliative management is based on need rather than diagnosis, and that capacity is decision- and not disease-specific, a closer alignment is required between the focus of any capacity and best interests assessments.

Three specific recommendations are put forward: Firstly the courts should adopt a patient-centred rather than clinician-centred approach to framing the decision that is subject to a capacity assessment. Secondly where a patient with Anorexia Nervosa lacks capacity, reliance on their stated treatment preferences must be balanced with their views and hopes regarding prognosis. The value of different treatment options should be assessed in this light. Thirdly given the clinical and ethical uncertainties regarding prognosis and appropriateness of treatment, there are dangers in relying on the same court-appointed expert in all cases.

I. INTRODUCTION

This paper considers medico-legal developments encompassing the treatment of people with severe and enduring Anorexia Nervosa (referred to in this paper by the acronym SEAN). Clinicians have only recently begun to use the term 'SEAN'.¹ There is disagreement as to when Anorexia Nervosa might usefully be labelled 'severe and enduring', what this means in terms of prognosis, and the consequences regarding treatment and management that flow from application of the label. This paper focuses on ways in which the law has in the past, and possibly might in future, resolve disputes about the care and treatment of patients with SEAN. There is growing recognition that

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¹ A term used in Mitchison D, Hay P, Engel S, Crosby R, et al. 2013. Assessment of quality of life in people with severe and enduring anorexia nervosa: a comparison of generic and specific instruments. *BMC Psychiatry*. 13: 1-9. Also referred to as SEED-AN: see Robinson PH, Kukucska R, Guidetti G, Leavey G. 2015. Severe and enduring anorexia nervosa (SEED-AN): a qualitative study of patients with 20+ years of anorexia nervosa. *European Eating Disorders Review* 23(4): 318-26.

treatment of SEAN can in some cases be considered futile,² in which case there is no legal basis to impose it on patients who cannot or will not consent. Patients with SEAN do not have a disorder of consciousness and can usually articulate their current views. This paper considers what reliance should be placed on those views both in determining whether a patient (who will be called 'P' in this paper) with SEAN has capacity and, where capacity is lacking, assessing P's best interests.

In England and Wales, section 1(5) of the Mental Capacity Act 2005 requires that where a person lacks capacity, decisions made on their behalf must be in their best interests. Section 4 sets out factors that must be considered in this assessment and whilst there is no legislative hierarchy within its provisions, the facts of each case will determine that some factors have particular weight. The UK Supreme Court decision of *Aintree University Hospitals NHS Foundation Trust v James (Aintree)* established that best interests must be determined from the perspective of the person who lacks capacity.³ Notwithstanding this development, the Law Commission reported in 2017 that the legal framework insufficiently prioritises the person's wishes and feelings.⁴ Decision-makers should not merely 'consider' wishes and feelings, but should 'ascertain' them as far as is practicable and give them weight, departing from them only where it is necessary and proportionate to do so.⁵ We argue that legal developments on the treatment of patients with SEAN fail to take a sufficiently patient-centred approach.

The article begins with a brief clinical account of treatment options for Anorexia Nervosa and the difficulties in recognising, labelling and treating severe and enduring cases. We then examine a series of five recent legal cases in which the respective judges advanced compassionate evaluations of whether compulsory treatment of patients with SEAN and other conditions should continue. The cases were heard in the Court of Protection, which has jurisdiction over financial and welfare matters for people who lack mental capacity. There follows an analysis of capacity, best interests and futility, and a proposal for greater alignment of the capacity and best interests assessments. The authors respectfully make three recommendations for future cases involving patients with SEAN. Though focussed on the Court of Protection, the recommendations flow from an analysis of universal principles of human rights and have resonance for international jurisdictions:

(1) The courts should take a patient-centred rather than clinician-centred approach to framing the decision that is subject to a capacity assessment. Whilst Anorexia Nervosa sometimes affects decision-making capacity in relation to nutrition, this does not preclude a finding that the patient has sufficient capacity regarding end of life decisions.

(2) Where a patient with Anorexia Nervosa lacks capacity, reliance upon their stated treatment preferences must be balanced with their views and hopes regarding prognosis. The value of treatment options should be assessed in this light.

² Westmoreland P, Mehler PS. 2016. Caring for Patients with Severe and Enduring Eating Disorders (SEED): Certification, Harm Reduction, Palliative Care, and the Question of Futility. *Journal of Psychiatric Practice* Jul;22(4): 313-20.

³ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [45].

⁴ Law Commission. 2017. Mental capacity and deprivation of liberty. Law Com No 372, 14.7.

⁵ *Ibid* 14.16 – 14.18 and rec 40; Draft Bill, cl 8(2) and (3).

(3) Given clinical and ethical uncertainties regarding prognosis and appropriateness of treatment, courts should appoint experts from a broad pool. There are dangers of relying on the same appointed expert in all cases.

II. SEVERE AND ENDURING ANOREXIA NERVOSA

Anorexia Nervosa is a serious and potentially life threatening mental health condition. Whilst it typically affects adolescents, it can also affect children and people into middle age,⁶ and, whilst many people who have Anorexia Nervosa are female, it also affects men. Voluntary treatment on an outpatient basis is often effective, but more serious cases may be referred to and treated by specialist eating disorder clinics and some of these people require hospitalisation. There is variation in the treatment and management of eating disorders within the NHS, there are chronic bed shortages⁷ and patients are not always admitted to the appropriate treatment setting.⁸

Where P's health or survival is threatened, P may be detained under sections 2 or 3 of the Mental Health Act 1983 (MHA). Section 63 of the MHA allows medical treatment for the disorder, without consent, including artificial nutrition.⁹ The most straightforward and common method of refeeding a patient is by gradually increasing the number of calories in an oral diet under supervision. For most patients, the requirement and expectation to eat, especially under the MHA, is sufficient. However, a small proportion of patients are unable to eat normally and require medically invasive feeding such as enteral nutrition, tube feeding. This carries its own risks, such as accidental feeding into the lung. This method of fluid and nutrition intake is sometimes acceptable to, preferred or even welcomed by patients with Anorexia Nervosa, as it limits choice and the burden of responsibility by bypassing the physical act of eating.¹⁰ For others, however, there can be efforts to refuse, manipulate or remove the tubes, which is dangerous. If resistance is sustained, this can lead to increasing conflict and restraint which consequently can then raise the spectre of forced feeding under physical restraint or pharmacological sedation.

Refeeding through any means can lead to complications. Sustained malnutrition leads to deficiencies of both macronutrients (such as carbohydrates and protein) and micronutrients (such as vitamins and minerals). Refeeding rapidly by any means without proper medical supervision can lead to potentially life-threatening metabolic

⁶ Micali N, Martini MG, Thomas JJ, et al. 2017. Lifetime and 12-month prevalence of eating disorders amongst women in mid-life: a population-based study of diagnoses and risk factors. *BMC Medicine* [Online] 15:12. See <http://dx.doi.org/10.1186/s12916-016-0766-4>.

⁷ See for example National Health Executive. 2016. National bed shortages force English anorexia patients to Scotland for care. 12th December. See <http://www.nationalhealthexecutive.com/Health-Care-News/bed-shortages-force-english-anorexia-patients-to-scotland-for-care>. And see proposals to tackle out-of-area placements for children and young people in Mental Health Taskforce. 2016. Five Year Forward View for Mental Health. See <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>.

⁸ The Royal Colleges of Psychiatrists, 2014. Physicians and Pathologists. MARSIPAN: Management of Really Sick Patients with Anorexia Nervosa. 2nd Edn. CR189, p 6. See <http://www.rcpsych.ac.uk/files/pdfversion/CR189.pdf>.

⁹ *B v Croydon District HA* (1992) 22 BMLR 13, CA; *Re KB (adult) (mental patient: medical treatment)* (1994) 19 BMLR 144; *Riverside Health NHS Trust v Fox* [1994] 1 FLR 614; Office of the Public Guardian. 2013 (updated 2016). MCA Code of Practice, 9.26.

¹⁰ See Tan J, Stewart A, Fitzpatrick R, Hope T. 2010. Attitudes of patients with anorexia nervosa to compulsory treatment and coercion. *International Journal of Law and Psychiatry* 33(1): 13-19.

changes, such as 'refeeding syndrome'.¹¹ Medical opinion differs as to the acceptability and efficacy of tube feeding voluntary patients. In some patients with Anorexia Nervosa, non-oral nutrition under varying degrees of compulsion may be the only option to maintain life. Naso-gastric tubes can be passed through the nose into the stomach; this is the commonest form of tube feeding but is only recommended for short periods. There are other forms of tube feeding such as Percutaneous Endoscopic Gastrostomy (PEG) feeding where a tube is surgically inserted into the stomach; or intravenous nutrition.

Eating disorders have the highest mortality rate of psychiatric disorders.¹² Approaches and treatments for Anorexia Nervosa are constantly evolving,¹³ but severe Anorexia Nervosa is amongst the most challenging mental health conditions to treat.¹⁴ Guidance from the Royal College of Psychiatrists¹⁵ focuses on reducing fatal outcomes, recognising that they sometimes result from 'inappropriate palliative care'.¹⁶ In 1997 the media reported the death of Nikki Hughes who had Anorexia Nervosa, stating that the NHS Trust treating her was given legal advice that her refusal of treatment could not be overridden.¹⁷ The MHA Commission issued guidance to the contrary,¹⁸ but reports of underfunding and confusion about the legal position persist.¹⁹ Some patients are not given access to the right support at the right time. It is noteworthy that neither the 2004²⁰ nor the replacement 2017 guidance²¹ issued by The National Institute for Health and Care Excellence (NICE) comments on the relevance of palliative management of Anorexia Nervosa, the emphasis being on timely and consistent treatment. As we shall see, future guidance may need to respond to developments in

¹¹ NICE. 2006. Nutrition support in adults. Clinical guideline CG32.

¹² Arcelus J, Mitchell AJ, Wales J et al. 2011. Mortality rates in patients with Anorexia Nervosa and other eating disorders: A Meta-Analysis of 36 Studies. *Archives of General Psychiatry* 68: 724-31.

¹³ See for example Park RJ, Singh I, Pike AC, Tan JO. 2017. Deep Brain Stimulation in Anorexia Nervosa: Hope for the Hopeless or Exploitation of the Vulnerable? *The Oxford Neuroethics Gold Standard Framework. Frontiers in Psychiatry.* 8: 44.

¹⁴ Steinhausen HC. 2002. The outcome of anorexia nervosa in the 20th century. *American Journal of Psychiatry* 159:1284-93; Goddard E, Hibbs R, Raenker S, et al. 2013. A multi-centre cohort study of short term outcomes of hospital treatment for anorexia nervosa in the UK. *BMC Psychiatry* 13: 287.

¹⁵ Royal College of Psychiatrists. 2014. *Management of Really Sick Patients with Anorexia Nervosa' (MARSIPAN) CR198.* And see *Junior MARSIPAN: Management of Really Sick Patients under 18 with Anorexia Nervosa. CR168.*

¹⁶ *Ibid*, p 30.

¹⁷ See Cooper G. 1997. Doctors get right to force-feed anorexic patients. *The Independent.* 5 August.

¹⁸ Mental Health Act Commission. 2004. *Guidance on the Treatment of Anorexia Nervosa under the Mental Health Act 1983.* See <http://www.seedeatingdisorders.org.uk/pdfs/user/F3774357-49CE-5BCB-F9BB-22ECC4C430E5.pdf>.

¹⁹ See The Masked AMHP. 2010. *Anorexia, the Mental Health Act – and Kayleigh.* See <http://themaskeamhp.blogspot.co.uk/2010/12/anorexia-mental-health-act-and-kayleigh.html>; BBC News. 2004. *Anorexia death to be investigated.* 4 February: See <http://news.bbc.co.uk/1/hi/health/3460189.stm>; Daily Mail. 2010. *'Skeletal' male chef suffering from anorexia and bulimia died while on daily diet of just two crackerbreads.* 29 June: See <http://www.dailymail.co.uk/news/article-1290635/Skeletal-male-chef-suffering-anorexia-bulimia-died-daily-diet-just-crackerbreads.html>; Tyler J. 2016. *Eating disorders nurse died weighing 5st after using her know-how to hide her own anorexia.* Birmingham Mail, 24 October: See <http://www.birminghammail.co.uk/news/midlands-news/eating-disorders-nurse-died-weighing-12072468>; BBC News. 2017. *Anorexic woman's death 'would have been prevented' with better treatment.* 2 February. See <http://www.bbc.co.uk/news/uk-england-devon-38825643>.

²⁰ NICE. 2004. *Eating disorders: core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders. Clinical Guideline CG 9.*

²¹ NICE. 2017. *Eating Disorders: Recognition and Treatment. NG69.*

the classification of Anorexia Nervosa that could lead to a growing acceptance of palliative management in the most severe and enduring presentations.

As outlined above, the responses to treatment for Anorexia Nervosa are varied and multi-faceted. Attempts to differentiate between types or stages of Anorexia Nervosa are relatively new. The term 'Severe and Enduring' has traditionally been reserved for certain mental health conditions typically characterised by psychosis but more recently has been applied so as to describe a classification of particularly durable Anorexia Nervosa.²² Hay and Touyz argue that the conceptualisation of staging models of Anorexia Nervosa has utility in assessment and treatment²³ but the staging of Anorexia Nervosa is not universally accepted²⁴. A variety of labels are used to denote an enduring form of Anorexia Nervosa²⁵ and the prognosis for patients who fall into this category is under-researched.²⁶

Ongoing analysis is needed to determine whether 'staging' of Anorexia Nervosa might or should lead to a greater acceptance of the withdrawal of active treatment in favour of purely palliative management of SEAN.²⁷ Questions around the suitability of palliative management in severe Anorexia Nervosa are hardly novel,²⁸ but its use has traditionally been determined by need rather than diagnosis. More recently, there have been calls for the palliative management of cases lasting more than ten years,²⁹ yet a recent longitudinal study found that around half of those who had not recovered from Anorexia Nervosa at 9 years, had recovered at 22 years.³⁰ From a clinical perspective at least, the study indicates that *routine* palliative management of SEAN is inappropriate.³¹ It also raises questions surrounding the ongoing treatment of the third of patients studied who were not recovered at 22 years. There is little data on treatment efficacy in such cases. Nor is it clear that clinicians can distinguish the longstanding patients who eventually recover from those who will not. Some argue that treatment

²² Hay PI, Touyz S. 2015. Treatment of patients with severe and enduring eating disorders. *Current Opinion in Psychiatry* 28(6): 473-7.

²³ Touyz S, Hay P. 2015. Severe and enduring anorexia nervosa (SE-AN): in search of a new paradigm. *Journal of Eating Disorders* 3: 26.

²⁴ Maguire S, LeGrange D, Surgenor L et al. 2008. Staging anorexia nervosa: conceptualizing illness severity. *Early Intervention in Psychiatry* 2(1): 3-10.

²⁵ Wildes JE, Forbush KT, Hagen KE et al. Characterizing severe and enduring anorexia nervosa: An empirical approach. *International Journal of Eating Disorders* 50(4):389-397; Broomfield C, Stedal K, Touyz S, Rhodes P. 2017. Labeling and defining severe and enduring anorexia nervosa: A systematic review and critical analysis. *International Journal of Eating Disorders* 50(6): 611-623; 2017.

²⁶ Hay PJ, Touyz S, Sud R. 2012. Treatment for severe and enduring anorexia nervosa: a review. *Aust N Z J Psychiatry*. 46: 1136–44. And see Touyz S, Le Grange D, Hay P, Lacey H (Eds). 2016. *Managing Severe and Enduring Anorexia Nervosa: A Clinician's Guide*. London: Taylor and Francis.

²⁷ Treasure J, Stein D, Maguire S. 2015. Has the time come for a staging model to map the course of eating disorders from high risk to severe enduring illness? An examination of the evidence. *Early Intervention in Psychiatry* 9: 173–184.

²⁸ Williams CJ. 1998. Does palliative care have a role in treatment of anorexia nervosa? *BMJ* 317(7152): 195–197.

²⁹ See Steinhausen HC. 2002. The outcome of anorexia nervosa in the 20th century. *American Journal of Psychiatry* 159:1284-93.

³⁰ Eddy KT, Tabri N, Thomas JJ, et al. 2016. Recovery from Anorexia Nervosa and Bulimia Nervosa at 22-Year follow-up. *Journal of Clinical Psychiatry* Dec 20. doi: 10.4088/JCP.15m10393: 31.4% of anorectic patients recovered in 9 years and 62.8% in 22 years.

³¹ The study focussed on patients with DSM-III-R/DSM-IV anorexia nervosa or bulimia nervosa.

should endure providing it is not rendered unviable by co-morbidities³² while others adopt the stance that SEAN can be a terminal condition, in which case palliative management is appropriate.³³ Depending on the viewpoint, compulsory treatment against P's wishes can thus be viewed as either ethically imperative or ethically unjustifiable.

Moves to reclassify some cases of SEAN as terminal are influenced by human rights developments protecting rights to individual autonomy and freedom from discrimination. The five cases discussed below each referred to the European Convention on Human Rights, the jurisprudence of which is influenced by the UN Convention on the Rights of Persons with Disabilities 2006 (CRPD),³⁴ though disappointingly the cases do not expressly reference the CRPD. The UN CRPD prohibits discrimination based on disability (article 4); states that the existence of disability does not justify deprivation of liberty (article 14); and protects the rights of persons with disability to 'enjoy legal capacity on an equal basis with others in all aspects of life' (article 12). Although the UK ratified the Convention in 2009, it remains unincorporated in English law, and it clashes with aspects of the MHA 1983 and the Mental Capacity Act 2005, that apply in England and Wales.³⁵

The paternalistic 'compassionate intervention' model³⁶ that sanctions compulsory refeeding for the good of the patient, gained credence on the basis of evidence that many patients who were coerced are later grateful for the intervention.³⁷ This model is losing force.³⁸ Draft NICE guidance charted a withdrawal of 'moral authority' for compulsory refeeding and the dawn of a 'more lenient approach'.³⁹ This development is not restricted to eating disorders. Consider recent proclamations that mental health units should supply sterile cutting equipment to some patients who self-harm on the basis that compulsion can exacerbate the problem. Sullivan argues for a harm minimisation model that recognises the value of supporting autonomy and independence.⁴⁰ As in cases of SEAN, the tensions are multi-faceted. Clinicians must

³² Collins Lyster-Mench L. 2016. There is no such thing as 'late terminal anorexia-nervosa'. Huffington Post 12 August. See http://www.huffingtonpost.com/entry/there-is-no-such-thing-as-late-terminal-anorexia-nervosa_us_5849c4e9e4b07d4bc0fa2605.

³³ See Schmidt S. 2016. Anorexic woman weighing 69 pounds has a right to starve, court rules. Washington Post 22 November: See https://www.washingtonpost.com/news/morning-mix/wp/2016/11/22/anorexic-woman-weighing-69-pounds-has-a-right-to-starve-court-rules/?utm_term=.08d50a6ef4ca, discussed below. AG was said to have 'late terminal anorexia nervosa'.

³⁴ See for example *Glor v Switzerland* (App. No.13444/04) (30 April 2009) and, more recently, *Çam v Turkey* [2016] ECHR 206 (23 February 2016).

³⁵ See Szmukler G, Daw R, Callard F. 2014. Mental health law and the UN Convention on the rights of persons with disabilities. *International Journal of Law and Psychiatry* 37(3): 245-252.

³⁶ Faith KE. 2002. Addressing Issues of Autonomy and Beneficence in the Treatment of Eating Disorders. National Eating Disorder Information Centre. See <http://nedic.ca/sites/default/files/addressing-issues-beneficence-and-autonomy-treatment-eating-disorders.pdf>.

³⁷ Watson T, Bowers W and Anderson A. 2000. Involuntary Treatment of Eating Disorders. *American Journal of Psychiatry* 157: 1806-1810.

³⁸ Law Commission. 2017. Mental Capacity and Deprivation of Liberty. Law Com No 372, 13.18.

³⁹ NICE. Draft: Eating Disorders - Recognition and Treatment. [GID-CGWAVE0703] p 31; See resulting guidance: NICE. 2017. Eating Disorders: Recognition and Treatment. NG69.

⁴⁰ Sullivan PJ. 2017. Should healthcare professionals sometimes allow harm? The case of self-injury. *Journal of Medical Ethics*. Published Online First: 09 February 2017. doi: 10.1136/medethics-2015-103146. Contrast Pickard H, Pearce S. 2017. Balancing costs and benefits: a clinical perspective does not support a harm minimisation approach for self-injury outside of community settings. *Journal of Medical Ethics*. Published Online First: 09 February 2017. doi: 10.1136/medethics-2017-104152.

balance the patient's preferences against their insight into the condition; the value of independence and control against compulsion; long-term against short-term harm minimisation; and management against cure. A plurality of views exists as to the prognosis and treatment options of patients with SEAN and yet in the five cases discussed in the next section, the court called each time on the specialist advice of the same expert: Dr Tyrone Glover. Whilst there is nothing whatsoever to suggest that this advice was not of the highest quality and integrity, it is respectfully submitted that the court would benefit from consideration of a broader range of clinical viewpoints.

III. THE CASES OF E, L, X, W AND Z

All of the five cases involved female patients over the age of 18⁴¹ who had suffered from Anorexia Nervosa for more than 14 years.⁴² In each case, a determination of the patients' best interests was made on the basis that they lacked capacity to decide.

Only in *Re E* did the court decide that in-patient treatment should continue. This was also the only case in which the judge referred to the term 'withdrawal of life-sustaining treatment'.⁴³ Nonetheless, in the cases of L, X, W and Z, none of the judges avoided the reality that they were in effect choosing between end of life options.⁴⁴

In the cases of L, X, W and Z, declarations were granted to the respective NHS Trusts allowing in-patient treatment to be withdrawn. The judges found there to be no available treatment offering a realistic prospect of significantly extending the patients' lifespans.⁴⁵ It was in each patient's best interests to be discharged from the MHA framework⁴⁶ in the hope that P would engage in voluntary treatment. Because that hope was negligible, the judges focussed on the inefficacy of continued compulsory treatment, considering the significant psychological and physical burdens it would entail. The patients were likely to resist refeeding by naso-gastric tube, so that restraint would be required. Taking each case in turn:

*Re E (medical treatment: anorexia) [2012]*⁴⁷

E was being treated in a palliative care setting, as previous treatment attempts had failed to affect a cure. The Official Solicitor and local authority sought a declaration that E be moved to an intensive care unit for refeeding. E's parents disagreed, arguing that palliative management was what E wanted. Peter Jackson J held that E lacked capacity to make decisions about life-sustaining treatment and that it was in her best

⁴¹ E was 32; L was 29; X a 'young woman'; W was 28; and Z was 46.

⁴² E for 21 years; L for 15 years, X for 14, W for 20 and Z for 31 years.

⁴³ *Re E (medical treatment: anorexia) [2012]* EWHC 1639 (COP), [5].

⁴⁴ *The NHS Trust v L and Others [2012]* EWHC 2741 (COP), [52] per Eleanor King J; *A NHS Foundation Trust v Ms X (Official Solicitor) [2014]* EWCOP 35, [44] per Cobb J; *Re W (medical treatment: anorexia) [2016]* EWCOP 13, [54] per Peter Jackson J; *Cheshire & Wirral Ptnr NHS FT v Z [2016]* EWCOP 56, [11] per Hayden J.

⁴⁵ *The NHS Trust v L and Others [2012]* EWHC 2741 (COP), [1], [7] per Eleanor King J; *A NHS Foundation Trust v Ms X (Official Solicitor) [2014]* EWCOP 35, [43] per Cobb J; *Re W (medical treatment: anorexia) [2016]* EWCOP 13, [49] per Peter Jackson J; *Cheshire & Wirral Ptnr NHS FT v Z [2016]* EWCOP 56 [9] per Hayden J.

⁴⁶ The procedural issues this raises are beyond the scope of this article but see *Cheshire & Wirral Ptnr NHS FT v Z [2016]* EWCOP 56, [21] per Hayden J.

⁴⁷ [2012] EWHC 1639 (COP).

interests to be forcibly re-fed. The 20-30%⁴⁸ chance of a full recovery that a 12-month (plus) programme of treatment might bring, justified any violation of her rights under Articles 3 and 8 of the European Convention on Human Rights. There was still hope for E:

We only live once – we are born once and we die once – and the difference between life and death is the biggest difference we know. E is a special person, whose life is of value. She does not see it that way now, but she may in future.⁴⁹

Sadly, there was evidence in *Re E* that E took pride in being ‘the most treatment-resistant patient they had ever had’.⁵⁰ In *A NHS Foundation Trust v X* it was noted that, two years on, E was still receiving treatment as an in-patient.⁵¹

E had twice made advance decisions refusing refeeding. The validity of an advance decision turns on evidence that the maker had capacity at the relevant time. A doctor had opined that E had the requisite capacity, but soon after felt that E was not expressing a consistent wish to die. In an apparent reversal of the burden of proof, Peter Jackson J concluded that, on the balance of probabilities, E lacked capacity at the time she signed the advance decision.⁵²

In its manner of presentation to the court, *Re E* differs from the other four cases. In *Re E* the Official Solicitor proposed continued treatment whereas in the other cases, the request was specifically about withdrawal of compulsory in-patient treatment. The open-endedness of the application in *Re E* did not go unnoticed. Peter Jackson J made clear that the court should not ‘be drawn into theorising’ but rather should be presented with available treatment options.⁵³ The Court of Protection is reluctant to decide hypothetical questions and proceedings are futile if there is no clinician willing to carry out proposed treatment.⁵⁴ *Re E* is the only case where continued in-patient treatment was recommended. It is quite possible that the following four cases were precipitated by the *Re E* decision.

The NHS Trust v L and Others [2012]⁵⁵

In *The NHS Trust v L*, L had spent around 90% of her life as an inpatient. She was physically frail and in end-stage organ failure. The evidence was that feeding via nasogastric tube would require sedation and ‘the likelihood of death if force-feeding were to be attempted on a chemically sedated basis would run at close to 100%’.⁵⁶ A robust case for withdrawal of coercive treatment was made out on the basis that continuing treatment would lead to psychological distress and quite likely result in death.

⁴⁸ Ibid [72], [90].

⁴⁹ Ibid [137], per Peter Jackson J.

⁵⁰ Ibid, [128].

⁵¹ *A NHS Foundation Trust v Ms X (Official Solicitor)* [2014] EWCOP 35, [56].

⁵² *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [135]. See discussion in Richardson G. 2013. Mental capacity in the shadow of suicide: What can the law do? *International Journal of Law in Context*. 9(1): 87-105.

⁵³ *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [41].

⁵⁴ *AVS v NHS Foundation Trust and B PCT* [2010] EWCA Civ 7.

⁵⁵ [2012] EWHC 2741 (COP).

⁵⁶ Ibid, [44].

A NHS Foundation Trust v Ms X (Official Solicitor) [2014]⁵⁷

X had a slightly better medical prognosis than L. Cobb J recognised that:

The particular tragedy of the case is that there is a possibility even now that Ms X could live a long and happy life, but that chance is very small indeed – less than 5%. Moreover, I am satisfied that she does not want to die.⁵⁸

X's life expectancy would be normal if she could stop drinking and resume a good diet.⁵⁹ However, alcoholism and severe liver disease posed additional risks in relation to any coercive refeeding regime, which resulted in a paradox: '[T]hat if I were to compel treatment, I may (and the doctors argue strongly that I would) be doing no more than facilitating or accelerating the termination of her life.'⁶⁰ Some of the risks associated with refeeding flowed from X's likely reaction to it. One possibility was that she would increase alcohol intake, another was that (if denied alcohol) she would attempt suicide.

Re W (medical treatment: anorexia) [2016]⁶¹

In W's case, the objections to refeeding under sedation focussed less on the chances that W would not survive the intervention and more on the ethical dilemmas inherent in a coercive regime:

The first proposal was for W to be re-fed under sedation. This would involve her being rendered unconscious for up to 6 months and fed by tube until she gained a BMI of 17.5. This proposal has not been pursued, rightly in my view. It is an unprecedented step and there were numerous potential objections about its ethical basis, W's objections, the unavailability of clinicians to carry it out, and the improbability that it would bring about sustainable change.⁶²

Recall that the same judge, Peter Jackson J, also presided in the case of E where it was accepted that:

She would be stabilised and fed with calorific material via a naso-gastric tube or a PEG tube inserted through her stomach wall. Any resistance would be overcome by physical restraint or by chemical sedation. The process would continue for a year or more.⁶³

Clearly refeeding under sedation is not itself 'unprecedented'.⁶⁴ The key difference between *Re E* and *Re W* for Peter Jackson J, was that for W all available treatment options, in a wide range of treatment settings had been tried to no avail.⁶⁵ In E's case, conversely, the evidence was that treatment options were not exhausted. Treatment could not at that point be considered futile.⁶⁶

⁵⁷ [2014] EWHC 35 (COP).

⁵⁸ *Ibid*, [11].

⁵⁹ *Ibid*, [24].

⁶⁰ *Ibid*, [42].

⁶¹ [2016] EWCOP 13.

⁶² *Ibid*, [20].

⁶³ *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [44].

⁶⁴ See Royal College of Psychiatrists. 2014. Management of Really Sick Patients with Anorexia Nervosa' (MARSIPAN) CR198, Appendix 6.

⁶⁵ *Re W (medical treatment: anorexia)* [2016] EWCOP 13, [18].

⁶⁶ *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [138]. 'I would not overrule her wishes if further treatment was futile, but it is not. Although extremely burdensome to E, there is a possibility that it will succeed.'

Re W concerns clinical futility of a different nature to *The NHS Trust v L* and *A NHS Foundation Trust v X*. It was enough in *Re W* that *W*'s Anorexia Nervosa was severe, unremitting and enduring. These factors indicated that a cure could not be hoped for.⁶⁷ *Re W* is thus the closest indication that the court might be amenable to the views that SEAN can potentially be considered terminal, compulsory treatment may be futile, and palliative management may be clinically appropriate.

Cheshire & Wirral Ptnr NHS FT v Z [2016]⁶⁸

The risks of harm associated with a coercive refeeding regime were considerable in *Z*'s case, though the evidence that it could lead to death was weaker than in *L* and *X*'s cases. The court differentiated between physical and chemical restraint, which posed different psychological and physical risks. Because *Z* had osteoporosis, physical restraint would probably result in musculoskeletal injury.⁶⁹ Chemical sedation posed a "very high risk" of respiratory or cardiac arrest as well as the risk that the sedation option could lead to some other iatrogenic cause of death'.

The next sections outline risks that flow from the potential interpretations of this series of cases. One is that clinicians might rely on the outcome of the cases without due consideration of the nuanced judicial examinations of the individual facts. This could potentially lead to both assumptions of incapacity in cases of SEAN and overreliance on the stated preferences of the patient when considering best interests. In future cases, it is argued that more could be done to protect *P*'s rights, will and preferences.

IV. CAN PATIENTS WITH SEAN HAVE MENTAL CAPACITY?

To understand the potential in practice for patients with SEAN to be assumed to lack capacity, we must first turn to the principles governing the Mental Capacity Act 2005 (MCA). The framework of the legislation has been articulated by Peter Jackson J in *Re E*⁷⁰ in the following terms:

People with capacity are entitled to make decisions for themselves, including about what they will and will not eat, even if their decision brings about their death. The state, here in the form of the Court of Protection, is only entitled to interfere where a person does not have the capacity to decide for herself.

By contrast, where a person lacks capacity, there is a duty to make the decision that is in her best interests.

The first question therefore is whether the person has capacity. The second, which can only arise if she does not, is what decision is in her best interests.

In all five cases, the court found that *P* lacked capacity. Anorexia Nervosa constitutes an 'impairment of, or disturbance in the functioning of, the mind or brain' so as to satisfy section 2(1) of the Mental Capacity Act test. Section 3(1) sets out the second stage of the two-part test:

For the purposes of section 2, a person is unable to make a decision for himself if he is unable—

⁶⁷ *Re W (medical treatment: anorexia)* [2016] EWCOP 13, [45].

⁶⁸ [2016] EWCOP 56.

⁶⁹ *Ibid* [16].

⁷⁰ *Re E (medical treatment: anorexia)* [2012] EWCOP 1639, [7]-[9].

- (a) to understand the information relevant to the decision,
- (b) to retain that information,
- (c) to use or weigh that information as part of the process of making the decision, or
- (d) to communicate his decision (whether by talking, using sign language or any other means).

In assessing P's capacity, the court is interested not only in the patient's understanding but also the ability to use and weigh the information. The MCA Code recognises that section 3(1)(c) concerning the ability to use and weigh information may be particularly pertinent to patients with Anorexia Nervosa.⁷¹ X was found to be unable to use and weigh the information relating to her Anorexia Nervosa, though she retained capacity in relation to her decision to imbibe alcohol.⁷² The evidence was that she could understand the information needed to make decisions about alcohol but not about food.

Two concerns about the capacity assessment of patients with Anorexia Nervosa are these: First, there is an assumption of incapacity in the terms of the declaration sought. In *A NHS Foundation Trust v X*, for example, the NHS Trust sought a declaration that it was not in X's best interests to subject P to treatment that may prolong life by compulsorily detaining and treating her against her wishes. This limited the court's scope to assess capacity, not because they could not refute the Trust's conclusion regarding capacity, but because it framed the decision with respect to which capacity is assessed, as one relating to refusal of nutrition. The second concern is articulated by Wang, who argues that the application of the MCA in *A NHS Foundation Trust v X* is incompatible with the UN CRPD.⁷³ If the decision was characterised as options between choosing a shorter life of better quality and a possibility of full recovery rather than simply as a refusal of refeeding, then P might, depending on their ability to understand, use and weigh these issues, retain capacity. The narrow focus prevented X from judging whether quality or duration of life was more important. The specific decision subject to an assessment of capacity was not necessarily whether to refuse or accept nutrition, but whether to refuse or accept treatment *that X considered futile*.

To focus on the narrow conception of P's refusal of treatment is, we would suggest, at odds with the position taken in the UK Supreme Court decision of *Montgomery*, a leading case on informed consent. The Supreme Court focused on P's entitlement to choose between relevant options⁷⁴ 'so that [P] is then in a position to make an informed decision'.⁷⁵ In the words of Lady Hale:

Most decisions about medical care are not simple yes/no answers. There are choices to be made, arguments for and against each of the options to be considered, and sufficient information must be given so that this can be done.⁷⁶

⁷¹ Office of the Public Guardian. 2013 (updated 2016). MCA Code of Practice, 4.22.

⁷² *X NHS Trust v T (adult patient: refusal of medical treatment)* [2004] EWHC 1279 (Fam), [28] –[30].

⁷³ Wang DWL. 2015. Mental Capacity Act, Anorexia Nervosa and the choice between life-prolonging treatment and palliative care: *A NHS Foundation Trust v Ms X*. *Modern Law Review* 78(5); 871-882.

⁷⁴ *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, [82], [87], [89] per Lords Reed and Kerr.

⁷⁵ *Ibid*, [90] per Lords Reed and Kerr.

⁷⁶ *Ibid*, [109].

The decision around treatment for SEAN is not simply a matter of saying yes or no to nutrition and neither should the assessment of capacity be confined to this issue.

V. CAN PATIENTS WITH 'SEAN' GIVE CAPACITOUS REASONS FOR REFUSING TREATMENT?

The last section argued that there are circumstances where the 'decision' in relation to which capacity is assessed should be the broader decision about quality and duration of life rather than the narrow issue of nutrition. If so, it might still be argued that the broader decision is strongly influenced by the Anorexia Nervosa, in which case it is important to ascertain in each individual case whether there are sufficient capacitous reasons to support the refusal of treatment.

There is authority for the proposition that a distinction should be drawn between cases where P cannot make a decision and cases where P's views are based, in part, on rational considerations. In *Re SB*⁷⁷, a 37-year-old woman with bipolar disorder was detained under section 2 of the MHA. Holman J held that, contrary to expert opinion, P retained capacity to elect the termination of her pregnancy at 23 weeks' gestation. Experts agreed that P understood what a termination entailed but was basing the decision upon 'flawed evidence and paranoid beliefs'.⁷⁸ The evidence was that P wanted the baby until the point at which she came off medication (probably to protect the baby) and was beset with paranoid thoughts. Her family considered the decision unwise, but Holman J made clear that, applying section 1(4) of the MCA, an unwise determination cannot be equated with an incapacitous decision. Holman J recognised that the views of experts are usually decisive: 'But those are generally cases in which the patient himself or herself is not positively and strongly asserting, and actually giving evidence, that he or she has the required capacity.'⁷⁹ SB was not 'unable to make a decision'. The experts asserted that P could not 'use or weigh' the information or process the consequences of the decision in accordance with section 3(4). But SB gave rational reasons for wanting an abortion that were not related to her paranoia: she did not want to have a child in detention or to have a child just to give it up for adoption.⁸⁰

Can rational reasons be given for refusing treatment for Anorexia Nervosa? Ambivalence is a feature of Anorexia Nervosa, with patients typically valuing the disorder and wishing to keep it, despite suffering and evidence of harm if they do not accept treatment.⁸¹ Furthermore, a challenge with severe Anorexia Nervosa is that patients are typically articulate, yet may have difficulties in separating an authentic self as opposed to a self which is inextricably entwined with the values, wishes and desires of Anorexia Nervosa. The attachment to Anorexia Nervosa can be so strong that patients may prefer to die than to gain weight, or value the disorder more than life itself. As a result, it is important to examine carefully what motivations and reasoning underpin P's expressed wish to live or to die. Thus, the question of whether P's will to die flows from a sense of hopelessness and a desire to end the struggle or alternatively

⁷⁷ *Re SB (a patient) (capacity to consent to termination)* [2013] EWHC 1417 (COP).

⁷⁸ *Ibid*, [34].

⁷⁹ *Ibid*, [36].

⁸⁰ *Ibid*, [41]-[42].

⁸¹ Hope T, Tan J, Stewart A, McMillan J. 2013. Agency, ambivalence and authenticity: the many ways in which anorexia nervosa can affect autonomy. *International Journal of Law in Context* 9(1): 20-36.

from an articulated preference to die rather than gain weight, is relevant when considering P's ability to use and weigh information.

There are parallels between *Re SB* and X, who also 'made a decision'. Whilst X's perception of her body image and weight were irrational, it is arguable that she also gave rational reasons for wanting to avoid further compulsion: X set out her views in writing, stating that the therapy was making her worse and: 'Whatever time I have left I just want to live each day alongside my granddad and [siblings], who are my world.'⁸² In a recent (as yet unreported) U.S. case, the Morristown County Superior Court in New Jersey (a state court with state-wide trial and appellate jurisdiction) ruled that a 29-year-old woman with SEAN referred to as Ashley G (AG), could not be treated against her capacitous decision to refuse food.⁸³ According to media reports, AG had previously been treated against her will and suffered heart failure because of refeeding syndrome.⁸⁴ Her Guardian argued that palliative care was appropriate and AG's parents agreed. Tube-feeding would likely result in musculoskeletal injury due to osteoporosis. The Department of Human Services and its Division of Mental Health and Addiction Services opposed the request but did not appeal the court's decision. As in X's case, AG understood that non-treatment could result in her death. Judge Paul Armstrong stated that her testimony was 'forthright, responsive, knowing, intelligent, voluntary, steadfast and credible'.⁸⁵ AG retained capacity and, in accordance with her wishes, she was transferred to a palliative care unit where she died.⁸⁶

Based on these five decisions from England and Wales, it is difficult to conceive of a case where someone with SEAN would be considered capacitous in relation to decisions to refuse food. Peter Jackson J recognised that E was in a Catch 22 situation: 'By deciding not to eat, she proves that she lacks capacity to decide at all.'⁸⁷ It seems that, by focusing the question on P's ability to make decisions about nutrition, we stray very close to a presumption of incapacity. We would respectfully recommend that in future cases, a patient-centred position is used to frame the decision which is subject to a capacity assessment. Even if the patient cannot make a capacitous decision about nutrition, they may be able to provide rational reasons for refusing treatment for Anorexia Nervosa. In such cases, clinicians or the court might accept that the patient can make a capacitous decision to do so.

VI. PARALLELS WITH ASSISTED DYING

As a brief but relevant aside, it is worth noting that questions surrounding the authenticity of treatment decisions made by those with mental disorder are not limited to Anorexia Nervosa. There are parallels with debates around assisted dying. Internationally, there is evidence of mounting acceptance of the right to assisted

⁸² *X NHS Trust v T (adult patient: refusal of medical treatment)* [2004] EWHC 1279 (Fam), [51].

⁸³ Schmidt S. 2016. Anorexic woman weighing 69 pounds has a right to starve, court rules. Washington Post. 22 November. See https://www.washingtonpost.com/news/morning-mix/wp/2016/11/22/anorexic-woman-weighing-69-pounds-has-a-right-to-starve-court-rules/?utm_term=.08d50a6ef4ca.

⁸⁴ *Ibid.*

⁸⁵ King K. 2016. Anorexic can refuse force-feedings, court rules. Wall Street Journal. 21 November. See <https://www.wsj.com/articles/anorexic-can-refuse-force-feedings-court-rules-1479777914>.

⁸⁶ Wright P. 2017. Anorexic, bulimic woman who fought force-feeding dies at 30. Associated Press. 22 February. See <http://news.findlaw.com/apnews/804b0c4fb3bd4fa4b7cd07b832d8cebf>.

⁸⁷ *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [53].

suicide.⁸⁸ In countries where assisted dying is lawful, it is often limited to terminal illness and sometimes also to non-terminal but presently incurable degenerative conditions, such as motor neuron disease. Conversely both the Netherlands and Belgium have recognised that, in principle, patients with non-somatic illness, such as clinical depression, are eligible for assisted dying. There are recent reports of a 20-year-old woman with Anorexia Nervosa accessing assisted dying in the Netherlands,⁸⁹ and of UK patients with dementia dying at the Dignitas facility in Zurich.⁹⁰ Schuklenk and van der Vathorst have argued that competent patients who suffer from depressive disorders that are treatment-resistant are discriminated against if they are excluded from the assistance in dying offered to other groups.⁹¹ The battle to ascertain and uphold the will of patients with mental disorder is one fought on a number of fronts.

VII. HOW FAR ARE P'S VIEWS RELEVANT TO AN ASSESSMENT OF BEST INTERESTS?

Given that the courts ruled that E, L, X, W and Z *lacked* capacity, the decisions turned on an assessment of their best interests. This section sets out the applicable test and considers the relevance of P's views. In the cases of L, X, W and Z, the judicial decisions coincided with each patient's stated wishes. It is difficult to discern from the cases how far this flowed from an attempt to comply with their will and preferences. This section affirms the importance of doing so, but also sounds notes of caution due to the difficulties of discerning will and preferences in cases of Anorexia Nervosa and the dangers of conflating the two.

Best interests cannot be defined by a single test.⁹² A balance sheet approach is often used as an 'aide-mémoire'⁹³ to assist in the weighing of medical and non-medical factors set out in section 4 of the MCA.⁹⁴ In *Aintree*, Lady Hale recognised the common law presumption that it is in P's best interests to stay alive.⁹⁵ Whilst there are no general principles applicable to when the presumption might be rebutted, there has been support for a 'touchstone of intolerability'⁹⁶ assessed by a balancing exercise.

⁸⁸ See, for example, *Carter v Canada (Attorney General)*, 2015 SCC 5, [2015] 1 SCR 331. Also Span P. 2017. Physician aid in dying gains acceptance in the UK. The New York Times. 16 January: reporting new assisted dying legislation in California (June 2016); Colorado (November 2016); Columbia (December 2016). See also dissenting judgments of Lady Hale and Lord Kerr in *R (Nicklinson) v Ministry of Justice; R (on the application of AM) v The Director of Public Prosecutions* [2014] UKSC 38.

⁸⁹ Doughty S. 2016. Sex abuse victim in her 20s allowed to choose euthanasia in Holland after doctors decided her post-traumatic stress and other conditions were incurable. Daily Mail. 10 May. See <http://www.dailymail.co.uk/news/article-3583783/Sex-abuse-victim-20s-allowed-choose-euthanasia-Holland-doctors-decided-post-traumatic-stress-conditions-uncurable.html>.

⁹⁰ Bodkin H. 2017. Struck-off psychiatrist helped six Britons to die in Swiss suicide clinics. The Telegraph. 22 January. See <http://www.telegraph.co.uk/news/2017/01/22/struck-off-psychiatrist-helped-six-britons-die-swiss-suicide/>.

⁹¹ Schuklenk U, Vathorst SVD. 2015. Treatment-resistant major depressive disorder and assisted dying. *Journal of Medical Ethics* 41; 577-583.

⁹² *R (Burke) v GMC (Official Solicitor intervening)* [2005] EWCA Civ 1003, [63] per Lord Phillips.

⁹³ *Re F (A Child) (International Relocation Cases)* [2015] EWCA Civ 882, [52] per McFarlane LJ warning that the balance sheet approach must be used as 'a route to judgment and not a substitution for the judgment itself'.

⁹⁴ *Re A (male sterilisation)* [2000] 1 FLR 549, 560 F-H per Thorpe LJ; *W v M and Ors* [2011] 1 WLR 1653, [222] per Baker J.

⁹⁵ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [35].

⁹⁶ *Ibid*, [37].

That exercise requires the decision-maker to consider ‘welfare in the widest sense, not just medical but social and psychological’.⁹⁷ This requires consideration of:

The nature of the medical treatment in question, what it involves and its prospects of success; 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 interested in his welfare, in particular for their view of what his attitude would be.⁹⁸

Lady Hale was clear that whilst the test is objective: ‘The purpose of the best interests test is to consider matters from the patient’s point of view’.⁹⁹ Where P cannot make a capacitous decision, then it is necessary to make an assessment of P’s values and beliefs, wishes and feelings in order to make ‘the choice which is right for him as an individual human being’.¹⁰⁰

This position brings the law closer to compliance with the UN CRPD. Article 12(4) views respect for P’s rights, will and preferences, as an integral part of equal recognition before the law. In 2017, the Law Commission recommended that P’s wishes and feelings should be ascertained and given weight¹⁰¹ and departed from only if necessary and proportionate.¹⁰²

In the five cases, P’s wishes are central to the analysis of best interests and in each case, P consistently and articulately stated a wish to avoid compulsory refeeding. In *Re E Peter Jackson J* said:

I agree ... that particular respect is due to the wishes and feelings of someone who, although lacking capacity, is as fully and articulately engaged as E.¹⁰³

In Z’s case, voluntary treatment was said to have the best hope of preserving Z’s autonomy.¹⁰⁴ In each judgment, credence was afforded to P’s views and in principle this is to be celebrated. In *Briggs v Briggs*, Charles J said:

if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life.¹⁰⁵

However, Charles J also recognised that the best interests determination is fact sensitive and exceptions may apply, for example, where P has previously made harmful decisions which the court would be reluctant to make on P’s behalf; where P’s current expression of their wishes (such as a desire to leave hospital) fails to factor in or weigh competing factors; and where clinical conditions and their effect impact on P’s decision-making.¹⁰⁶ These factors are highly relevant to the SEAN cases. Anorexia Nervosa can undermine autonomy in several ways,¹⁰⁷ and though ‘will’ and

⁹⁷ Ibid, [39].

⁹⁸ Ibid, [39].

⁹⁹ Ibid, [45].

¹⁰⁰ Ibid, [45].

¹⁰¹ Law Commission. 2017. Mental Capacity and Deprivation of Liberty. Law Com No 372, 14.7.

¹⁰² Ibid 14.16–14.18 and rec 40; Draft Bill, cl 8(2) and (3).

¹⁰³ *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [127] and see [132].

¹⁰⁴ *Cheshire & Wirral Ptnr NHS FT v Z* [2016] EWCOP 56, [19] per Hayden J.

¹⁰⁵ *Briggs v Briggs* [2016] EWCOP 53, [62].

¹⁰⁶ Ibid, [60].

¹⁰⁷ Hope T, Tan J, Stewart A, McMillan J. 2013. Agency, ambivalence and authenticity: the many ways in which anorexia nervosa can affect autonomy. *International Journal of Law in Context* 9(1): 20-36.

'preferences' are often conflated,¹⁰⁸ the SEAN cases serve as a powerful illustration of how the two might clash. There may, for example, be a stated preference (not to eat) that conflicts with an authentic will (to live); a current preference contradictory to a past preference; or the Anorexia Nervosa might itself influence or generate a willingness to die (though not usually a wish to die) that flows from the desire to be thin, in which case P's 'rights' may conflict with both P's will and preferences.

Coggon persuasively argues that, where possible, the same weight should be given to P's wishes and feelings when P lacks capacity as when P retains it.¹⁰⁹ The MCA requires by section 4(6) that consideration is given, as far as is reasonably ascertainable,¹¹⁰ to P's past and present wishes and feelings, beliefs and values. As Coggon acknowledges, difficulties arise where P has expressed conflicting views. Does a past capacitous view take precedence over a current incapacitous view? Section 4 of the MCA gives little guidance as to how to deal with conflict between past and present wishes. In SEAN cases, it may not be clear whether P ever possessed the relevant insight into their condition such that P could make a capacitous decision about nutrition. There was some acknowledgment of this in Z's case: Having considered the 'broader canvass' of Z's life,¹¹¹ Hayden J concluded: 'Sadly, in this case that has proved to be a very short exercise. Z's world, since she was 15 years of age, has been entirely circumscribed by her eating disorder.'¹¹²

Analysing *Cheshire & Wirral Ptnr NHS FT v Z*, Clough convincingly demonstrates that consideration of will and preferences must go beyond a mere consideration of the issue of nutrition.¹¹³ As we have seen, all five patients wanted to avoid a coercive regime, but whilst E and X wanted to be allowed to die with dignity¹¹⁴ L, W and Z expressed a hope and desire to live. L felt that if funding were secured to enable her to move to a nursing home, she would survive.¹¹⁵ W wanted to return to education and pursue a career.¹¹⁶ Z believed that, if allowed to return home, she would survive.¹¹⁷ Given the conflicting nature of the desire to live and the desire to avoid compulsory refeeding, it is unclear in L, W and Z's cases which should take priority.

¹⁰⁸ Committee on the Rights of Persons with Disabilities. 2014. General Comment No 1: Article 12 Equal Recognition Before the Law. CRPD/C/GC/1. See discussion in Skowron P. 2015. Will, preferences, and the danger of confusing wants and needs – some thoughts on the UNCRPD. University of Manchester School of Law Blog. See <http://blog.law.manchester.ac.uk/will-preferences-and-the-danger-of-confusing-wants-and-needs-some-thoughts-on-the-uncrpd/>.

¹⁰⁹ Coggon J. 2016. Mental capacity law, autonomy, and best interests: An argument for conceptual and practical clarity in the Court of Protection. *Medical Law Review* 24(3): 396-414. And consider *Winspear v City Hospitals Sunderland NHS Foundation Trust* [2015] EWHC 3250 (QB), where Blake J found that the duty to consult before issuing a DNACPR notice applied equally in respect of patients with and without capacity.

¹¹⁰ See reform proposals: Law Commission. 2017. Mental capacity and deprivation of liberty. Law Com No 372, 14.16–14.18 and rec 40; Draft Bill, cl 8(2) and (3).

¹¹¹ As per *Re S (adult patient: sterilisation)* [2001] (Fam) 15; *County Durham & Darlington NHS Foundation Trust v SS* [2016] EWHC 535 (Fam).

¹¹² *Cheshire & Wirral Ptnr NHS FT v Z* [2016] EWCOP 56, [13].

¹¹³ Clough B. 2016. Anorexia, capacity, and best interests: Developments in the Court of Protection since the Mental Capacity Act 2005. *Medical Law Review* 24 (3): 434-445.

¹¹⁴ *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [76]. *A NHS Foundation Trust v Ms X (Official Solicitor)* [2014] EWCOP 35, [50].

¹¹⁵ *The NHS Trust v L and Others* [2012] EWHC 2741 (COP), [31].

¹¹⁶ *Re W (medical treatment: anorexia)* [2016] EWCOP 13, [28].

¹¹⁷ *Cheshire & Wirral Ptnr NHS FT v Z* [2016] EWCOP 56, [14].

Just as we have argued that the capacity assessment should look beyond the narrow issue of nutrition, so too, where P lacks capacity, the best interests assessment should extend beyond that narrow focus. The danger inherent in the five cases is twofold. Firstly, it is not clear that a sufficiently nuanced consideration of best interests was undertaken. Secondly, it is possible that the cases may be misconstrued in practice and that patients shown (or assumed) to lack capacity will nonetheless be given the choice to refuse treatment. Unless a suitably nuanced consideration of will and preferences is undertaken, there is potential in clinical practice to assume that the stated preferences of the patient represent their best interests where, in some cases, in-patient treatment might still be appropriate and potentially efficacious.

VIII. TREATMENT UTILITY AND FUTILITY

In England and Wales, the issue of treatment efficacy - that is, how effective a proposed treatment is likely to be in the opinion of the clinician - influences clinicians' choices between two different but overlapping legal regimes: The Mental Capacity Act 2005 and the Mental Health Act 1983. We have shown that there is much debate as to the efficacy of treatment in cases of SEAN and this section explores the impact of that uncertainty.

Mental Health Act

As we have seen, in-patient treatment under the MHA 1983 does not necessarily require patient consent. A minimum requirement is that the treatment does not violate Article 3 of the ECHR, which prohibits inhuman or degrading treatment. Compulsory treatment violates Article 3 unless shown to be in P's best interests on the basis that a 'medical necessity has been convincingly shown to exist'.¹¹⁸ In *R (N) v (M)* the test for necessity was said to include:

- (a) how certain is it that the patient does suffer from a treatable mental disorder; (b) how serious a disorder is it; (c) how serious a risk is presented to others; (d) how likely is it that, if the patient does suffer from such a disorder, the proposed treatment will alleviate the condition; (e) how much alleviation is there likely to be; (f) how likely is it that the treatment will have adverse consequences for the patient; and (g) how severe may they be.¹¹⁹

Where the treatment decision is made by clinicians under the MHA framework, the first factor listed in *R (N) v (M)* is affected by a revision of the MHA in 2007, which replaced the requirement of treatability with one of 'appropriate' treatment.¹²⁰ This affords clinicians significant discretion. How the discretion is exercised will depend, in part, on the clinician's position on whether the particular case of Anorexia Nervosa can and should be classified as 'severe and enduring' and the effect they believe this has on treatment efficacy. Clinicians who consider the disorder to be a chronic condition might see value in continued treatment. The MHA Code of Practice recognises that for some patients, management rather than cure is 'all that can be hoped for'.¹²¹ In common with many mental health disorders, eating disorders cannot always be cured

¹¹⁸ *Herczegfalvy v Austria* [1993] 15 EHRR 437, 484; *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [126].

¹¹⁹ [2002] EWCA Civ 1789, [19] per Dyson LJ.

¹²⁰ Mental Health Act 1983 s 58(3)(b), as amended by the MHA 2007. See Bartlett P. 2011. Standards for compulsory treatment for mental disorder under the Mental Health Act 1983. *Medical Law Review* 19(4): 514-547.

¹²¹ Department of Health. 2015. Mental Health Act 1983 Code of Practice. TSO, paras 6.15-6.16.

and a diagnosis may be life-long. In these cases, treatment under the MHA might continue. On the other hand, some, who accept that a case is severe and enduring, will also accept that compulsory treatment is no longer efficacious, in which case it may no longer be apposite to treat under the MHA. Media reports of the U.S. case of AG, discussed above, go so far as to classify that case of Anorexia Nervosa as a 'late terminal' condition.

Mental Capacity Act: Cure or management?

If treatment is no longer considered appropriate under the MHA, the MCA regime remains relevant. In *Briggs*, Charles J recognised that P's views might not be followed if P wants something that 'is not an available option'.¹²² In the five SEAN cases, P was not requesting, but refusing, treatment. Still, the perceived utility or futility of the treatment options is pertinent: A refusal of something that would not be offered needs little by way of justification. The right to life enshrined in Article 2 of the European Convention on Human Rights is not absolute¹²³ and the best interests test goes wider than medical necessity¹²⁴ to encompass the value of treatment.¹²⁵ In *Aintree*, Lady Hale made it clear that futility must be assessed against the wide interests of the patient; treatment is not futile if it brings benefit to the patient, even if it does not improve the underlying medical condition.¹²⁶

Unfortunately, the cases evince dicta suggestive of a more limited view of the purpose of treatment. When combined with a narrow focus on P's expressed views, the judgments form a powerful incentive for clinicians to release objecting SEAN patients from in-patient treatment programmes. The dicta in question focus on cure as the purpose of treatment. In *W*'s case, it was said that interventions had for some time merely kept her alive rather than addressed the underlying condition.¹²⁷ To keep P on the unit or move P to another unit was considered cruel given the restrictions it would involve and the remoteness of any prospects for change.¹²⁸ In *X*'s case, too, it was established that the purpose of refeeding was not simply to avert the risk of death, but rather to treat the underlying conditions. The purpose was for *X*:

- i) to gain weight,
- ii) more importantly to gain insight into the benefits of psychotherapeutic interventions to address the causes of her illnesses, and then
- iii) yet more crucially still, to avail herself of those psychotherapeutic interventions.¹²⁹

The conclusion in *X*'s case was that: 'Any refeeding treatment would not now, as it never has, address the cause of the Anorexia Nervosa; it would merely serve to prolong life'.¹³⁰ In *Z*'s case, the judge concluded that discharge from the MHA

¹²² *Briggs v Briggs* [2016] EWCOP 53, [60].

¹²³ *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [120] and *The NHS Trust v L and Others* [2012] EWHC 2741 (COP), [18] citing *Airedale NHS Trust v Bland* [1993] AC 789.

¹²⁴ *Re S (sterilisation: patient's best interests)* [2000] 2 FLR 389.

¹²⁵ Office of the Public Guardian. 2013 (updated 2016). MCA Code of Practice, 5.31.

¹²⁶ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [40], [44] per Lady Hale.

¹²⁷ *Re W (medical treatment: anorexia)* [2016] EWCOP 13, [38].

¹²⁸ *Ibid* [40].

¹²⁹ *A NHS Foundation Trust v Ms X (Official Solicitor)* [2014] EWCOP 35, [41] per Cobb J.

¹³⁰ *Ibid* [43].

framework and treatment on a voluntary basis 'is ultimately the only proposal which carries any vestige of hope and most effectively preserves Z's dignity and autonomy'.¹³¹

Coggon argues that the concept of the treatment decision needs further evaluation.¹³² The narrow view of the purpose of treatment is potentially at odds with Lady Hale's assertion in *Aintree* that: '[I]t is setting the goal too high to say that treatment is futile unless it has 'a real prospect of curing or at least palliating the life-threatening disease or illness from which the patient is suffering'.¹³³

We have suggested above that the decision against which capacity is assessed should encompass P's decision surrounding the value of further treatment. We would further argue that this approach should extend to best interests assessments so as to take account of whether a short- or long-term view of the purpose of treatment is *relevant* to P. A short-term view may be relevant in cases where the prognosis is poor but prolonged life coincides with the patient's will or values.¹³⁴ It might also be relevant to a SEAN case if there is evidence that refeeding could enhance capacity (by reducing the adverse effects of physical frailty or sedative drugs); or that refeeding might lead to a more positive engagement with services, family or education, even if the evidence suggests that P might later relapse. The closer we come to assessing futility of treatment options against the goal of complete cure, the easier it will be to demonstrate. This may be failing P if it coincides with their stated preference but not their will or values and their desire to live.

IX. CONCLUSION

The judges in the decisions of E, L, X, W, and Z carefully and compassionately considered the patients' wishes. In four of the cases they granted the declarations sought by the NHS Trusts to cease compulsory treatment in compliance with the wishes of each P, with the support of their families and clinicians.

This paper has focussed on the human rights implications of the judgments in law and clinical practice. It is important to acknowledge that the judges operated under several constraints. Firstly, they were limited by the options put to them by the clinical team. There is no general power to decide how clinicians should treat a patient.¹³⁵ Secondly, the courts were powerless to affect the timing of the decisions. NHS Trusts are advised to bring a claim only once a structured assessment has taken place,¹³⁶ but by the time the cases of E, L, X, W and Z came to court, the condition of each of the patients was dire.¹³⁷ Finally, the question of resources is an ever-present undercurrent.¹³⁸ NICE has

¹³¹ *Cheshire & Wirral Ptnr NHS FT v Z* [2016] EWCOP 56, [19] per Hayden J.

¹³² Coggon J. 2015. Alcohol dependence and anorexia nervosa: Individual autonomy and the jurisdiction of the Court of Protection: *An NHS Foundation Trust v Ms X* [2014] EWCOP 35. *Medical Law Review* 23; 659-67.

¹³³ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [43].

¹³⁴ See for example *St George's Healthcare NHS Trust v P&Q* [2015] EWCOP 42.

¹³⁵ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [18] per Lady Hale.

¹³⁶ *St George's Healthcare NHS Trust v P&Q* [2015] EWCOP 42.

¹³⁷ See *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [40]. And on importance of timing of application more generally, see *Sandwell and West Birmingham Hospitals NHS Trust v CD* [2014] EWCOP 23.

¹³⁸ But see *Re E (medical treatment: anorexia)* [2012] EWHC 1639 (COP), [143]: 'I record that the state, having instigated this plan of action for E in the way that it has, is now honour bound to see it through

acknowledged that 'eating disorders, in particular Anorexia Nervosa, result in substantial economic burdens upon healthcare resources'.¹³⁹ Clinicians must consider the resource implications of on-going treatment, just as treatment availability or lack thereof¹⁴⁰ may have paradoxically contributed to the severe and enduring nature of the condition now suffered by the patient.

Operating within these constraints, it may yet be possible in future cases to subject a clinical view that P lacks capacity to greater scrutiny. This would allow judges to enhance protection of P's autonomy rights and to provide valuable practical guidance for clinicians. We have made three principal recommendations that aim to put the rights, will and preferences of P at the heart of decision-making:

(1) The court should resist appointing the same expert in all cases. In a clinical setting, a plurality of views exists on the staging and classification of Anorexia Nervosa, prognosis of patients with SEAN, their capacity, the choice between Mental Capacity Act or Mental Health Act regimes, and ultimately their best interests. Understood as a potentially *terminal* condition, the focus might be on when to stop treatment and focus on palliative management. Understood as a *treatable* or indeed *chronic* condition, the focus will be on refusal of refeeding in which case, even if capacitous, P's refusal might be overruled under the MHA framework on the basis that appropriate treatment and prospect of recovery or continued life with reasonable quality exists.

(2) A patient-centred assessment of capacity will flexibly interpret the decision about which capacity is assessed by reference to the patient's views on the value of treatment. A patient who lacks capacity to make a decision about nutrition may have capacity to determine that treatment is no longer worthwhile.

(3) Where it is found that P lacks capacity, and the Court of Protection is asked to determine best interests, the Court should seek to identify P's views, contrasting current and past views; rights, will and preferences. Exclusive focus on P's expressed views on refeeding risks reliance on stated preferences that can potentially clash with P's will (as, for example when P refuses food but desires to live). This is particularly troublesome when P's (unauthentic) views of futility coincide with a clinical view that treatment of SEAN has become futile, or with a judicial assessment of the appropriateness of treatment against the goal of cure rather than management of the disorder. Where P expresses views about the value and purpose of treatment, these views are relevant to the best interests assessment. Where they constitute an authentic expression of P's will, they will guide clinicians and the court in determining best interests from P's point of view.¹⁴¹

Though the judgments do not promote such a broad-brush approach, a focus on the outcomes of the five cases in combination might lead to an assumption, in clinical practice, that P cannot make a capacitous decision in relation to the treatment of SEAN, and, where a lengthy programme of intervention has not addressed the

by the provision of resources in the short, medium and long term. Had the authorities not made that commitment, I would not have reached the conclusion that I have.'

¹³⁹ NICE. Draft: Eating Disorders - Recognition and Treatment. [GID-CGWAVE0703], p 35.

¹⁴⁰ NHS Confederation, Mental Health Network. 2016. Funding for Mental Health. 15 June: Reports a £600m real-term fall in NHS mental health funding over the course of the last parliament. See <http://www.nhsconfed.org/resources/2016/06/funding-for-mental-health>

¹⁴¹ *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [45].

underlying condition, that further compulsory treatment might be considered futile. This can and should be avoided. Palliative management should be based on need rather than diagnosis; capacity should be decision- and not disease-specific.