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Eating and drinking with acknowledged risks: 3 years on

16 May 2024

Welcome & housekeeping

Judith Broll
Director of Professional Development, RCSLT

Housekeeping

- Justyna Szeller (RCSLT Host) is on hand to help with any **technical queries**; you can get in touch with her via the **chat button**
- You can send in **questions** to our speakers today by using the **Q&A button**
- This event is being recorded and will be made available on the RCSLT website along with the presentation slides
- We want this event to be a safe and inclusive space for all delegates. We ask that you are respectful of other delegates views and experiences and you show compassion

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CEO Welcome

Steve Jamieson
CEO, RCSLT

Eating and drinking with acknowledged risks

Dharinee Hansjee RCSLT
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https://www.rcslt.org/wp-content/uploads/2021/09/EDAR-multidisciplinary-guidance-2021.pdf

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Ethical frameworks provide a critical eye for when working through clinical examples but it is not a replacement for human rights David Kaye

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“We’ve been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive.”
Atul Gawande
Advisor To The Conversation Project
the conversation project

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Lived Experience

There is so little I have control over, I want to choose what to eat and drink

Holding a glass of wine made me feel part of the wedding

I hope that more people with dementia are treated like individuals

I would rather risk choking than have that tube in me

It's good to see I have a choice

Eating and drinking is so much more than nutrition

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Proportionality

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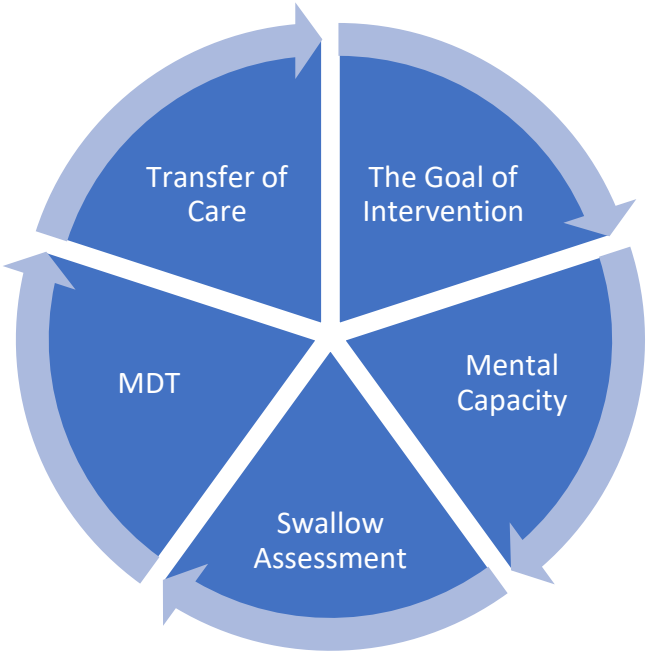
Shared Decision-Making Recommendations



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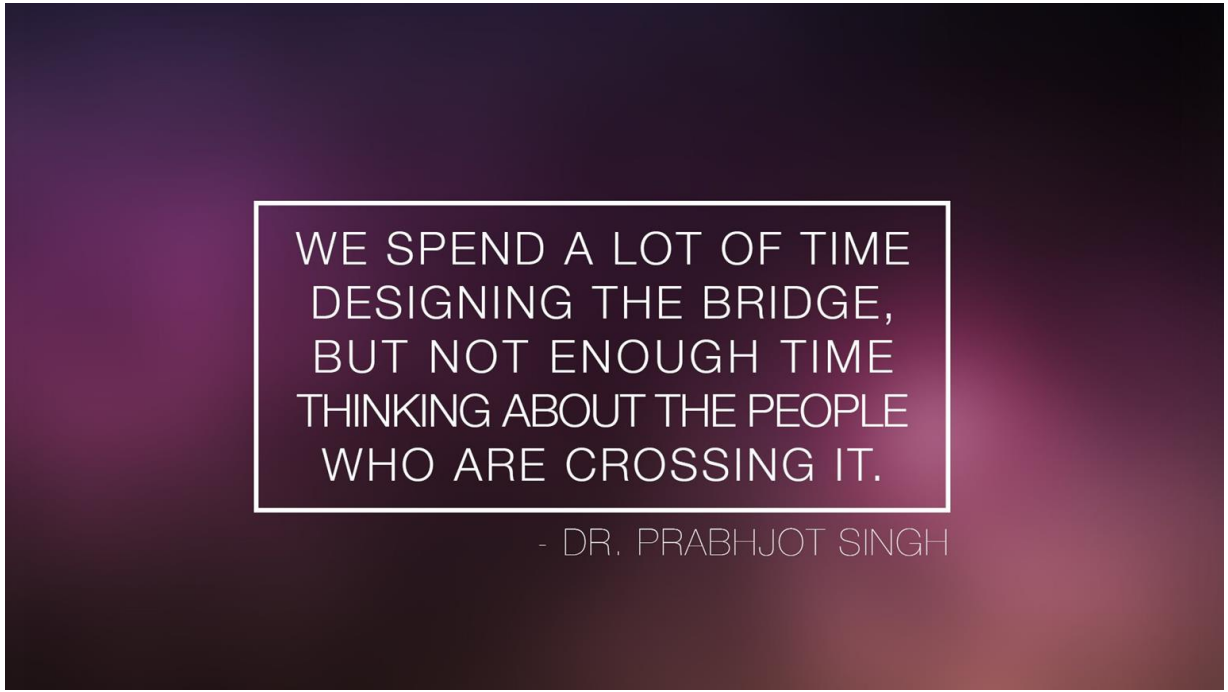
WE SPEND A LOT OF TIME DESIGNING THE BRIDGE, BUT NOT ENOUGH TIME THINKING ABOUT THE PEOPLE WHO ARE CROSSING IT.
- DR. PRABHJOT SINGH

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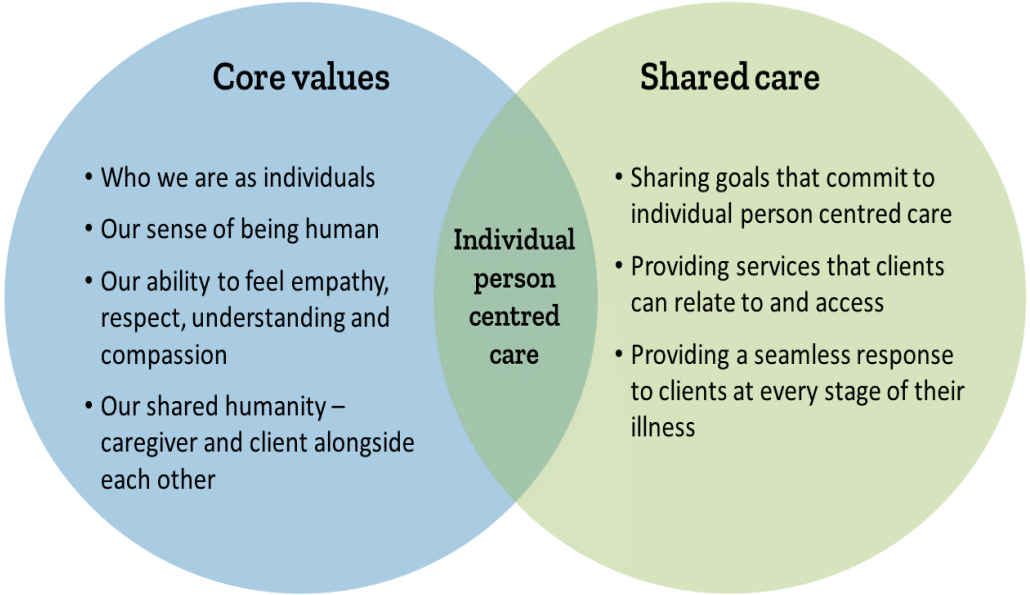
Person Centred Care



https://www.homelesspalliativecare.com/shared-care/

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Dignity

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Evidence

The clinical condition of the patient, other diagnoses and risk factors

+ Choice

The individual's wishes, values & beliefs

= MDT Decision

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Where are we at?

- Quality of life (RCSLT position paper on use of Thickened Fluids; 2024)
- Aspiration Pneumonia & Dysphagia (O'Keefe et al, 2021)
- Consensus on Terminology
- Ethical Dilemmas in SLT Education
- Protocols & Policies

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Enablers and barriers to protocols

Capturing processes on one document

Personalising care

Improving transfers of care

Outlining MDT roles & responsibilities

Misuse to expedite discharge

Poor information handover

Focus is on aspiration rather than optimising nutrition & hydration

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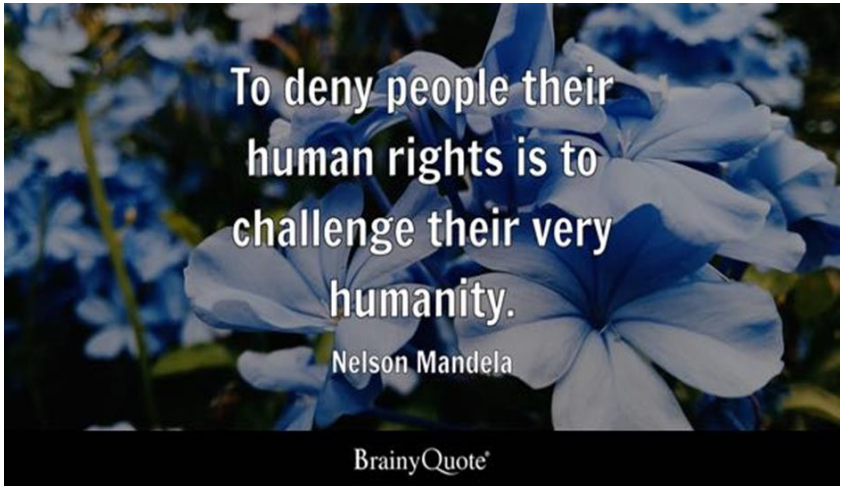
Reflections



- How would the consideration of the EDAR guidance, have impacted on care for JJ?
- Should food be classed as treatment or a fundamental choice?
- Do we sometimes over medicalise care?
- Are we using the guidelines to ensure a robust person-centred decision or to protect ourselves as staff (defensive medicine)? (O'Keefe et al, 2021)

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- Anantapong, K., Bruun, A., Walford, A., Smith, C. H., Manthorpe, J., Sampson, E. L., & Davies, N. (2023). Co-design development of a decision guide on eating and drinking for people with severe dementia during acute hospital admissions. *Health Expectations*, *26*(2), 613-629.
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Eating and drinking at acknowledged risk post *JJ*

May 2024

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Pre-JJ Guidance: RCP

in any 'risk feeding' decision, there needs to be a calibration between being risk averse, and placing carers in an impossible position in the name of patient autonomy

[...] an adult with capacity can choose to make a decision which appears to others to be unwise. That could include a decision that they wish to be fed in a way that puts them at risk. If the person has understood and accepted that risk, then, as long as the carers who act upon their request have acted with due care, they should not be exposed to any liability if the person does, in fact, suffer adverse consequences. However, there are circumstances in which the carers may feel that the risks are so great that they cannot properly respond to the individual's request. In such cases, all those concerned (including relevant professionals and others interested in the person's welfare) should consider whether there are ways in which the risks can be mitigated. It may be that some members of the MDT conscientiously feel that they cannot take part in feeding even at a mitigated level of risk, while others are willing to do so. If (1) the risks of the relevant route cannot be mitigated to a degree sufficient to satisfy the concerns of the team as a whole; and (2) the patient still wishes only to receive nutrition and hydration by that route, then legal advice should be sought as to whether a court application is required, for instance that a declaration that the team are not under a duty to provide nutrition and hydration in the fashion chosen by the person, even if the end result is their death.

RCP Supporting people who have eating and drinking difficulties (2021)

Pre-JJ Guidance: RCP

There may be circumstances in which it is clear that a patient lacking capacity to make the relevant decisions wishes to be fed in a specific fashion, but the team conscientiously consider that this would place the person at an unacceptably high level of risk. In such a situation, responsibility for the risk does not lie, ultimately, with the patient because they lack capacity. Rather, it lies with the team responsible for their care. This means that a best interests decision could properly be taken that another route should be adopted to secure nutrition and hydration. Exceptionally, it might be sufficiently clear that the patient would not find that alternative route acceptable so that to assist them to eat and drink in that fashion could not properly be said to be in their best interests. Again, at that point, legal advice should be sought as to whether a court application is required.

The approach set out above is **not** intended to serve as a licence for either individual decisions to be made or policies adopted based upon undue risk aversion. Rather, it reflects the fact that the law recognises that, notwithstanding the importance of respecting the rights of individual patients to make their own decisions, the law does not require those involved to be placed in situations that they conscientiously consider either undignified or dangerous.

See, by analogy, *R(A & Ors) v East Sussex County Council & Anor* [2003] EWHC 167 (Admin)

Pre-JJ Guidance: RCSLT

While the Royal College of Physicians (RCP) document ‘Supporting people who have eating and drinking difficulties’ (2021) is the primary guidance for care and clinical assistance towards the end of life, this document will serve as an adjunct referring to the nuances within the decision-making process for adults eating and drinking with acknowledged risks irrespective of the stage or progression of their illness.

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Pre-JJ Guidance: RCSLT

The overall goal of this document is to support the decision-making process irrespective of the person having the capacity to accept the risks involved. As emphasised in the RCP guidance (2021), a person with capacity can choose to make a decision which appears to others to be unwise. That could include a decision that they wish to receive nutrition in a way that heightens risk to their general health. There may also be circumstances in which it is clear that an individual lacking capacity to make decisions wishes to receive nutrition in a specific fashion which appears to pose a risk to them. If there is a proper consideration of whether this is in their best interests, then those who act upon that known wish will be protected from liability, again so long as they have acted with due care.

R (JJ) v Spectrum Community Health CIC [2023] EWCA Civ 885

- An appeal from a decision of a judge to refuse a claim for judicial review in respect of Spectrum's refusal to feed him, a quadriplegic prisoner, certain foods of his choice
- Spectrum declined to give JJ snacks in the form of boiled sweets, biscuits and crisps in the interests of safety and in circumstances where to do so would, they believed, risk exposing their staff to criminal or regulatory proceedings should JJ come to harm as a consequence of eating foods which are not within his prescribed soft diet ('Level 6 diet').
- JJ was +/- consistently refusing food
- JJ had made an ADRT confirming that food refusal was to apply even when his life is at risk and that he did not wish to be ventilated or to have cardiopulmonary resuscitation

JJ: key questions

- A question of choice or of clinical appropriateness?
- The definition of “medical treatment”

JJ: a question of choice?

68. The common law authorities so far considered therefore establish (i) that a patient with capacity can choose between various treatment options, which choices have to be respected by the clinicians even if the treatment chosen is not the one that was recommended by the treating team and (ii) a patient with capacity can refuse medical treatment. That then leaves the question as to whether, as advocated by Ms Weereratne, there is a common law right of autonomy which allows a patient to demand, and obliges a clinician to provide, medical treatment that is not offered to that patient by their doctors.

- An “unequivocal no” (paragraph 69)
- Not helped by Article 8 ECHR right to autonomy as an aspect of private life

JJ: the definition of medical treatment

The provision of food is treatment or care for the purposes of medical treatment decisions. Where, as here, the patient is unable to feed themselves, all foods such as boiled sweets are part of treatment or care: *Airedale NHS Trust v Bland* [1993] AC 789 at p 858G

- Nb *Bland* concerned artificial nutrition and hydration, not (3rd party) hand-provided food…

JJ: the regulatory / prosecutor fears

Under CQC regulation 22 (2), Spectrum could be prosecuted where a breach of regulation 12 has resulted in a patient being exposed to 'avoidable harm or significant risk of such harm occurring'. As the judge found, under regulation 12, Spectrum must provide safe care and treatment. There is no 'consent defence' under the CQC Regulations which permits a healthcare provider to provide care which it considers carries unacceptable risk. I agree with the judge that it is not fanciful to regard Spectrum as being at risk of prosecution under regulation 22(2) for being in contravention of regulation 12 if JJ choked and died having been given boiled sweets by Spectrum in circumstances where they had commissioned and understood the contents of the SALT assessment.

There is also the potential for Spectrum and its staff to be vulnerable to prosecution under the Health and Safety at Work etc Act 1974.

In support of his submission that the judge had equally been right in finding that the risk of criminal prosecution was not fanciful, Mr Glenister took the Court to R v Adomako [1994] UKHL 6 where the required elements to satisfy the legal test for gross negligence manslaughter were endorsed and defined by the House of Lords. Lord Mackay said in his speech that:

> "The jury will have to consider whether the extent to which the defendant's conduct departed from the proper standard of care incumbent upon him, involving as it must have done a risk of death to the patient, was such that it should be judged criminal."

JJ: the aftermath

- A change in the law or a clarification of a previously (? helpfully) grey area?
- ‘Hard cases make bad law’
- A fact-specific risk assessment: not a judicial endorsement of risk aversion
- Judicial review proceedings so no independent assessment of the risks identified by Spectrum

JJ: responding realistically

- Negotiation about acceptable methods of feeding
- Being realistic about risk – ALARP will carry weight
- The possibility of approaching the courts:
  - Capacitous patient: High Court declaration that lawful to feed in the presence of risk
  - Incapacitous patient: Court of Protection for best interests decision
- But there will be limits to the courts' willingness / ability to give a 'get out of jail free' card

Section 44 MCA 2005 – an analogy?

The purpose of s 44 of the Act is clear. Those who are in need of care are entitled to protection against ill-treatment or wilful neglect. The question whether they have been so neglected must be examined in the context of the statutory provisions which provide that, to the greatest extent possible, their autonomy should be respected. [...]. On analysis, the offence created by s 44 is not vague. It makes it an offence for an individual responsible for the care of someone who lacks the capacity to care for himself to ill-treat or wilfully to neglect that person. Those in care who still enjoy some level of capacity for making their own decisions are entitled to be protected from wilful neglect which impacts on the areas of their lives over which they lack capacity. However s 44 did not create an absolute offence. Therefore, actions or omissions, or a combination of both, which reflect or are believed to reflect the protected autonomy of the individual needing care do not constitute wilful neglect. Within these clear principles, the issue in an individual prosecution is fact specific."

R v Ligaya Nursing [2012] EWCA Crim 2521

More resources

- 39 Essex Chambers | Mental Capacity Law | 39 Essex Chambers | Barristers' Chambers
- Mental Health & Justice | (mhj.org.uk)
- Mental Capacity Law and Policy
- MCA Directory | SCIE
- Mental Health Law Online

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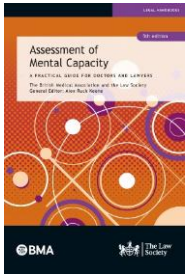

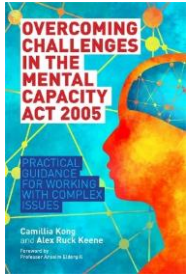

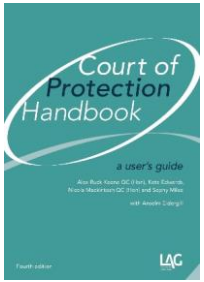

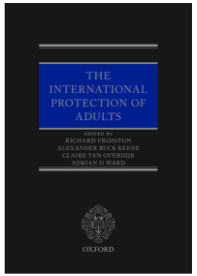

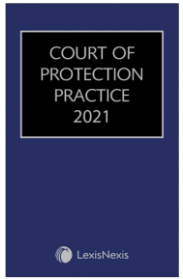

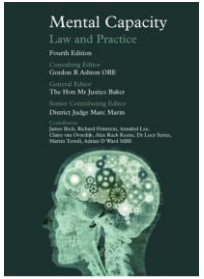

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Questions?

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Evaluation

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Thank you

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