# **Eating and drinking with acknowledged risks**

## Frequently asked questions - July 2024

In 2021, RCSLT released its guidance on eating and drinking with acknowledged risks to support those working with adults to understand their role and how best to support service users and those involved in decision making. Our [webinar](https://www.youtube.com/watch?v=lFyY3PMCUGQ) in May 2024 explored the guidance further. The following questions were asked before or during the webinar and we would like to thank Dharinee Hansjee and Alex Ruck Keene KC for their knowledge and insight in providing the answers. We recommend that you watch the webinar and the follow-up short [video](https://youtu.be/LKAuEazh1t0) by Alex Ruck Keene KC. NB RCSLT are currently working with RCSLT Scotland to confirm any potential differences between legislation in Scotland and will update this document in due course.

### Risk

#### Q: Considering the limitations of the evidence base, how do we communicate the severity and likelihood of the risks identified within this process?

A: Protocols are useful in guiding us through different aspects of care. For example, within dementia there is a significant amount of evidence discussing quality of life versus artificial nutrition and hydration. The clinical swallowing assessment will identify a multitude of factors impacting on swallow, not just the person’s ability to swallow different consistencies and textures but also contributory factors such as position, mouth care and levels of dependency which are all key markers to determine levels of risk. It is also important to consider medication administration when considering the severity and likelihood of risk. Objective assessments may be beneficial in some circumstances, particularly for the capacitous individual from a visual, educational perspective.

#### Q: How do we shift from a risk averse culture to a risk enablement approach?

A: We advise to use a person-centred approach and have a clear clinical picture as well as understanding the person’s wishes. We have been taught that we must eliminate risk; therefore, the thought of being central to these decisions can sit uneasy with us or other professionals. One should consider that there are risks with all intervention’s actions i.e. artificial nutrition and hydration. We need to consider is our intervention about eliminating the risks or managing them. If risks come from not knowing what we are doing, then it stands that frameworks such as the eating and drinking with acknowledged risks (EDAR) guidance helps us to consider the risks. Guidance such as this and the [Royal College of Physician’s guidance on ‘Supporting people who have eating and drinking difficulties’](https://www.rcplondon.ac.uk/file/28796/download) reminds us to treat the person and not the condition with the best available tools. Through including the discussion of EDAR in the pre-registration curriculum we are reframing the discussion about risk from an earlier level of professional development

#### Q: How do we ensure EDAR is not over generalised in vulnerable populations?

A: It is essential to look at the individual. Reflect on what encapsulates person-centred care. Are we considering the cultures and traditions of the individual or are we looking at their condition and assuming what will be best for them. Be brave and ask why they are or aren’t a suitable candidate for EDAR. Established policies and procedures can support these discussions to ensure that agreed best practice within the organisation is adhered to. In legal terms, if you are making assumptions about particular groups this is very likely to be discrimination. For example, if someone says ‘we don’t put artificial nutrition and hydration tubes into people with learning disabilities’ this is discrimination.

#### Q: Does it come down to ultimately documenting risk vs benefit and the decision? Will there be templates coming out from college we can use?

A: RCLT will not develop a UK wide template as it would be impossible to do this taking into consideration the specifics of every situation, scenarios and local policies and procedures. However, we are going to host a resources page where examples of templates will be stored, and people can access this to support development of their own local framework.

#### Q: What about people in community with history of chest infections, but are not showing overt signs of aspiration on modified diet/ fluids, have never received a videofluoroscopy and could be silently aspirating? We often don't know what the risks are if the person is not able to access instrumental assessments.

A: It is important here to consider the full clinical picture rather than swallowing in isolation. The SLT must work to uncover the chest history and explore its potential relationship with swallowing difficulties or other related factors. What is the presenting condition/ is there a diagnosis? If there is a pattern of repeated chest infections and the clinical swallowing evaluation did not flag up concerns about choking then an instrumental assessment is usually warranted which will help establish the underlying physiology of the swallow, if the person is indeed silently aspirating and guiding towards an intervention. However, it is important to remember that instrumental assessments are a snapshot in time and need to be interpreted with all the additional information surrounding the person. The situation becomes more complicated if the person is unable to access an instrumental assessment. Clear and ongoing monitoring or chest status, eating, drinking and swallowing ability can help to build a clinical picture. Discussions should be made with the service user/carer around the limitations of the information gathered and taken into consideration when making a decision around EDAR.

#### Q: Do you feel the increasing use of models such as ‘DIGEST’ which allocated risk to safety and efficiency is going to be helpful in these circumstances?

A: We are not familiar with DIGEST but usually any model that is being implemented to improve the quality of the decision-making process within EDAR can only be helpful. A suggestion would be to weigh up these models against the recommendations outlined in the EDAR document to ensure all aspects are being considered for that organisation and client population.

### Roles

#### Q: What is the SLT role and what is their responsibility?

A: Conducting a through specialist assessment, advocacy, ensuring information is accessible. In some organisations it is the SLTs responsibility to complete mental capacity assessments related to nutrition. The SLT should ensure they link with the relevant professionals and everything is documented in accordance with organisational policy. Shared decision making is complicated as you are sharing with the person and team and then within the team there may be varying levels of responsibility. The person who is notionally holding responsibility for the decision is not necessarily the person who is in most contact with the service user and they may have different perspectives to those who have regular contact with the service user. It is imperative to establish a functioning team for these purposes and is even more important where the service user lacks capacity. Within England and Wales under the Mental Capacity Act you do not have a designated decision maker. Best interest decision making and capacitous decision making is an essential part of clinical governance. Each team members contribution should be recognised and valued and have the ability to raise concerns if they feel the wrong decision is being made.

Within England and Wales, as the SLT would not normally be the person in overall charge of the person’s care, and, although the MCA doesn’t provide for formal decision-makers, in practice it will be the consultant or GP who is having to decide on the course of treatment (taking into account everyone’s views), because it is they who put their name to the care plan. Those people who are actually then implementing it will be taking their cue that their actions are covered because they are acting on a care plan which they understand to reflect proper consideration of the patient’s capacity and best interests. There may be a situation where the SLT is in overall charge of the person’s care and wants to decide on the appropriate course of treatment, we would advise that if this is the case the person contacts RCSLT via info@rcslt.org to discuss further. Please note this would be an exceptional situation and not the norm.

#### Q: Do we need medical sign off of this decision from clinical and legal perspectives and will there be different answers depending on whether the patient has capacity or not?

A: There is no legal requirement for a specific person to carry out a specific action in any given situation. The law demands a coherent plan being drawn, responsibility being taken, and reasonable steps being taken to think about e.g. capacity, best interests etc. However, within a hospital setting, Consultants often want to have ultimate sign off of these decisions. Within community settings some GP’s may be agreeable to have a team decision and then be informed of the outcome. Therefore, it is essential to understand the policies and procedures within your organisation and ensure there is effective communication between the key players. (Also, please see previous answer)

#### Q: I have worked with someone who has severe learning disabilities and a history of chest infections for years. It is my opinion that although this person has dysphagia, this is not the only contributing factor to him having ongoing chest infections. He has very complex medical history which I think plays a part. I am pursuing a EDAR best interest meeting with his carers, GP etc. The gentleman doesn't have capacity. I know I can't be the decision maker, but how can I influence the risk being wider than just dysphagia in this situation?

A: Can you involve other medical consultants or gain access to reports which show how their other medical conditions are contributing to the chest infections. Often dysphagia is not the only factor in contributing to chest infections therefore all the other factors need to be taken into consideration e.g. mobility, oral health. Are all the other conditions being managed as effectively as possible and how have the other conditions been considered as a contributory factor within overall eating, drinking and swallowing management. For example, if he has COPD is this being managed effectively, is he showing any signs of gastroesophageal reflux, is his breath swallow coordination or positioning impacting on swallowing. Think of it as building a picture of the person as a whole and presenting this to the team.

#### Q: Community issue: What happens when there is no wider MDT involved with a client, as they are in their own home. There is only a GP and you are unable to make contact with the GP, only via letter. Taking into account that the person will have to eat and drink as they cannot be left as nil by mouth. What would the best way to tackle this?

A: Establishing a relationship with the GP and highlighting the importance of the joint decision-making process are key. If the GP is not willing to engage then you can look to other professions where someone may be a best interest assessor and is in overall charge of the person’s care i.e. social work, occupational therapy, nursing or psychology. First port of call, however, would be to involve the GP. Emailing a letter would keep a track of the discussions if you were challenged at a later stage. If the GP is unwilling to be involved you may need to escalate your concerns to your manager and seek appropriate support within your organisation.

### Reaching consensus

#### Q: If a family member, informal carer or person with lasting power of attorney (LPA) disagrees with the EDAR decision i.e. either to EDAR or not to EDAR, what steps should the SLT take, and should it be escalated to the legal/safeguarding team?

A: If we assume the person does not have capacity to make a decision re EDAR i.e. there is a best interests decision/discussion. There is no identified surrogate decision maker within England and Wales. Instead, it is a collaborate decision where everyone’s views are taken into account and a decision is made as to the correct course of action. Although this is a good system, where it falls down is where there are differences of opinion. This requires action as to how the disagreement is addressed to ensure we are acting within the person’s best interests. We need to consider where this objection is coming from e.g. is it the family members personal fears or is it recognition of what the person would or wouldn’t want. With regards to a lasting power of attorney, assuming it is for health and welfare, is registered with the office of the public guardian, if the attorney disagrees with the recommendations from the team, then we do not have agreement and need to think it through. Consider if e.g. the person with LPA has new information which could alter the decision. Within England and Wales, if you are unable to reach agreement, then the only person who can decide is a court of protection judge and not the office of the public guardian. This is also the route where the team are unable to make an agreed decision. An independent mental capacity advocate (IMCA) needs to be involved if it is a serious intervention or the consequences are serious and is being proposed by an NHS body and the person is unbefriended i.e. there is no one professionally involved in their care and an IMCA must be instructed. Whether an IMCA needs to be involved in a decision around EDAR depends on the consequences and who is involved in the decision making. Where there is not a duty to appoint an IMCA there is no requirement to involve them. It is important to have an open discussion with all involved where the information is accessible to their needs and talks about the risks and benefits of all courses of action e.g. artificial nutrition and hydration as well as EDAR.

### Future planning

#### Q: How do we holistically make EDAR decisions and plan for future care when the patient may move between settings and /or their condition change?

A: Working with the clinical effectiveness team to write a policy to ensure all the necessary stakeholders are involved and get to comment on the content, the processes, the relevant systems. This is also the informal endorsement of the training around EDAR. It is lengthy and time consuming but valuable in bringing everyone onboard and owning the process. It is sometimes the role of the SLT in being proactive to explain assessment results and concerns, demonstrating where we add value to the process to develop a culture of working together for our service users. Documentation and communication remain core to ensuring holistic EDAR decisions are made and adhered to.

### JJ Vs Spectrum Healthcare legal case

#### Q: The impact of the JJ case has had significant impact on care homes i.e. they are struggling to understand the implications. What are your reflections on this?

A: The JJ case has exposed that people who want to be risk averse will be risk averse, people who recognise that is not what this case was saying will understand that you cannot eliminate all risk and that if the team involved conscientiously consider that they cannot stomach the action, then they can’t be forced to carry it out. The message is not ’never take any risks’. This case has been a stress test of the mantra ‘we’re putting the patients first’. We need to consider how much the organisation can think through risk, how much can it be mitigated, how can we work with service users but to also recognise that there is a space at times within a team to recognise that they cannot carry out what is asked of them. Through the JJ case, there has been huge organisational learning about how we work with other organisations and understanding the regulatory requirements they are under, their targets. It is essential to work together to set up a process that works for you and have adequate documentation. See NICE guidance 27 which has a useful infographic on the benefit of information sharing.

#### Q: With reference to the JJ case did Spectrum / team speak to the original SLT who had put the recommendations in place as they would have been able to further assess or provide input.

A: JJ did have a further appointment but due to a variety of factors the SLT felt they were unable to assess at that time. Following this, JJ refused any further reassessment unless it was guaranteed he would be given the foods he requested from then onwards. When the SLTs couldn't guarantee this, he refused reassessment.

### Adults without capacity to make decisions around eating and drinking with acknowledged risks

#### Q: For adults with advanced dementia who have been determined to lack the capacity to make decisions around EDAR, what action should be taken considering artificial nutrition and hydration where research has shown it is not beneficial.

A: For adults who do not have the capacity to make decisions around eating and drinking at risk we advise that national and local policies on best interest decision making is followed. This should be a multidisciplinary decision that is person centred and involves the person's representative. Potential risks and benefits of all proposed options should be considered and presented to the team involved along with the rationale for the final decision documented. This may include decisions around the clinical appropriacy of non-oral nutrition. Each individual should be reviewed on their own unique characteristics.

#### Q: If a patient is not eligible for enteral feeding and EDAR is the only option, are carers liable for prosecution for supporting with feeding in an EDAR case? As this opens up potential liability to anyone supporting someone who is EDAR.

A: No, in this situation where there is no alternative but to feed the person, they would not be liable. However, they would need to follow the agreed best interest decision as to how the risk is reduced e.g. bolus size, consistency, positioning and if they did not follow these then they could be potentially liable.

### Mental capacity

#### Q: What is the SLT role in mental capacity assessments, best interest assessments and deprivation of liberty with regards to EDAR.

A: SLTs are not currently on the list of best interest assessors although they can assess mental capacity. Deprivation of liberties (DoLs) for people with dysphagia may occur if, for example, a person has the physical ability to feed themselves but who lacks capacity to understand potential choking risks. A DoLs may be put in place to restrict their access to certain foods e.g. an ambulant person in a care home with dementia who attempts to access foods seen as a choking risk. For the vast majority of people DoLs is not a consideration. The key message is that if you as an SLT have determined someone does not have capacity you cannot make the best interest decision to EDAR but should contribute to the decision-making process. Please see section on roles.

#### Q: Question about a specific case: I work with an adult with LD who, after some traumatic changes in her life, started eating large amounts of foods that put her at risk of choking. Multiple choking incidents have occurred in the last 6 months. She is supervised during the day but takes food from the fridge into her room during the night. Staff are worried about her choking risk when unsupervised and liaised with social care re fridge lock. I completed a mental capacity assessment and it appeared that she was able to understand, retain, and weight risks associated with her food choices. Supporting staff are now questioning whether a fridge lock would be inappropriate considering she appears to have capacity. I am unsure how to advise staff in terms of weighing her own choice / capacity against the very real risk of choking during the night when unsupervised.

A: This is a complex case, and the fridge lock could potentially be considered a deprivation of her liberties. We would advise discussing with you safeguarding and legal teams.

#### Q: If a patient is deemed as having capacity to make the decision around EDAR - can we just document that and that decision stand - or do we need a GP/Consultant to "rubber stamp" this?

A: It depends upon the individual circumstance and whether they for example need someone to feed them as the decision is no longer just theirs but affects others therefore a more thorough process needs to occur. It is best practice to work with the service user and team to discuss the implications of their decision and what support they may need following this. For example, an advance care plan may need to be put in place.

#### Q: If a patient has an EDAR decision in place, but their swallow improves and no longer at risk does the decision needed revoking by a medic or is SLT documentation of this alone enough?

A: This would depend on whether they had capacity or not and the nuances of their situation. If they had capacity, it could potentially be straightforward and the SLT could document and communicate this to all involved; however, if a best interest decision was in place as they didn't have capacity, they would need the best interest decision reviewed by an appropriate individual e.g. GP or Consultant.

### Paediatrics

#### Q: The current RCSLT EDAR guidance is for adults only. Will guidance on paediatrics be produced and what should we do in the interim.

A: RCSLT is aware that there is a gap in guidance around paediatric EDAR guidance. Upon the next review of the EDAR guidance we want to incorporate paediatric guidance into this document. Work on this will start at the very earliest late 2025. In the interim we would advise that you seek supervision from someone with specialist knowledge in this area if this is an issue within your practice. If you are unable to access supervision and need support from RCSLT please email info@rcslt.org and we will support you. Other useful sources of information can be gained via CENs and study days. This [article](https://www.rcslt.org/wp-content/uploads/2023/09/BULLETIN-Autumn-2023.pdf) was published in 2023 in Bulletin and has a useful overview of paediatric EDAR

### Liability

#### Q: Say the person coughs and shows signs of aspiration at every meal, videofluoroscopy shows variable presentation but is chest infection free. Staff, family and the person (via non-verbal cues) wish to continue oral nutrition only. If we document a best interest decision, can the carer be held liable for harm?

A: We can never say that someone would be 100% free from the risk of future prosecution. However, if all persons involved were in agreement it would be very unlikely that this would happen.

#### Q: Would you advise going to legal every time a situation is this complicated? What if the individual has multiple acknowledged risks of aspiration, has capacity but also needs assisting like JJ? I have a case just like it and now very nervous.

A: Where the situation is complex and particularly where there is disagreement between the person involved and/or members of the team we would advise escalating to your legal and safeguarding teams.

#### Q: Following informed discussion, the patient decides to EDAR. The videofluoroscopy recommendations are for using thickener e.g. Level 2. Would you as the SLT be liable, if say the family decide to pursue this in court suggesting medical negligence (in the event the person passes away)? Would you recommend that patients sign a document to note that informed discussion was held and they made this informed decision? I know some commentators have moved away from a waiver, however if it is framed in a more person-centred way with an informed discussion document?

A: Practice around asking a service user to sign a waiver needs to be determined at an organisational level with consideration of e.g. best interest processes and paperwork. We would recommend that any documentation is completed in accordance with local record keeping standards and information governance procedures. It is very unlikely that the SLT would be seen as liable if the person had capacity and all the benefits and risks were fully explained to them, documented and agreed. If the person did not have capacity this would need to be escalated to safeguarding.

#### Q: We know that artificial nutrition and hydration does not stop people getting chest infections. How do we then consider that as the ultimate end point? e.g. legally it would be considered that not all options have been explored if a PEG hasn't been explored?

A: There are 3 factors to consider within this question:

* progression/clinical picture
* quality of life
* Choices and preferences

Some acute teams will have a document on the PEG form for the SLT to report on swallowing. There needs to be a clear rationale for PEG insertion due to the above factors and risks being inevitable despite oral intake or PEG

### Choice

#### Q: A service user with capacity has a choice as to which treatment they receive. But that choice is not a choice of everything, it's only a choice of the things that the clinicians deem are appropriate for this patient?

A: Yes. The service user can refuse but not demand a treatment/intervention. The care provider should discuss the most appropriate interventions from all the possible interventions along with the potential risk and benefits of each

#### Q: How is this supporting pt choice and autonomy (with reference to JJ case)?

A: This is a very difficult one as we need to balance the choice and rights of all those involved not just the service user. We need to consider how the choices and actions of the individual have an impact on those around them where those people may not be able to follow their requests in all good conscience.

### End of life care

#### Q: Please could you shed light on who, if anyone, is authorised to make a NBM decision for someone with palliative stage dementia and dysphagia? Am I right in thinking that a SLT should always be involved when a doctor/nurse may think NBM is the best option for such a patient?

A: Good practice would be to involve the SLT so that a full assessment of swallowing can happen to ensure that NBM is the most appropriate action.

### Care providers/carers

#### Q: Thinking about the case Alex brought, our team has had discussions about concerns care homes will take this ruling and become increasingly risk adverse/refuse to agree with EDAR discussions/decisions that we feel would be appropriate for a patient. What would happen in this case/how do we manage this?

A: This very situation has occurred in some parts of the country. We have worked with members and the care providers to explain the specifics of this ruling and what best practice looks like. The SLT departments have worked to develop their organisational EDAR policy and documentation as well as providing education to care home staff. If this does happen to you, please email info@rcslt.org and we will support you.

#### Q: I was wondering if there are any additional points regarding a care home resident without capacity, recommendations given for modified diet and fluids, family visit and provide items which are unmodified (family had agreed to modifications in care home). Family is stating they are unable to read or write. Care home wants to serve notice due to risk carers feel when family bring in items unsuitable for resident. Resident appears to have reduced distress with modifications.

A: In this case you would need to ensure that every effort has been made to educate the family on the most appropriate textures to bring in. If the service user is showing fewer signs of distress with the items family are bringing in, it may prompt a review from the SLT to look at this and consider it within the context of their overall dysphagia management plan. If family continue to offer inappropriate items, then a safeguarding referral should be made. If the person does not have capacity, were the family involved in the best interest decision making process and did they agree to the recommendations.

### Free water protocol

#### Q: Would you be able to speak about EDAR in relation to the free water protocol please?

A: The Frazier Free Water Protocol (FFWP) offers a risk-reducing structure to support oral intake of water. Some service users may choose to follow the protocol as a way of mitigating the risk of oral fluid intake and it may be an appropriate option to discuss with some service users depending on their circumstances. The role of the SLT is to educate service users about the options available to them with the risks and benefits discussed and also how any potential risks may be lessoned or removed. Although the protocol may be an option for some people, it is important to consider the impact on their psychological and emotional help of restricting oral intake to water only

### Organisational level

#### Q: How would you advise approaching organisational wilful ignorance e.g. refusal to attend dysphagia training and human resources supporting this decision?

A: It is essential to get a policy in place, in this way you get the clinical effectiveness team on board. There will be consultation of the document/content, version controls on the policy and training/education will need to form part of the implementation. This means that the organisation must be responsible for adherence to the policy, e.g. if it states within the policy that all medics must attend swallowing training, and this is not being achieved then it can be escalated to the clinical effectiveness team or governance teams. Some other ways this situation may be mitigated is by getting onto the medical/nurse training programmes to engage with colleagues, get a slot on academic half days, attend clinical governance to report issues you are finding or promote the policy. The geriatricians are generally great allies with implementation of EDAR. Also, as an SLT department how have you flagged this concern and what steps are you taking to address it i.e. are incident reports being completed, is the topic on the organisation’s risk register.

### Resources

#### Q: Are there any further plans from the RCSLT to help SLT's engage GP's in EDAR decisions?

A: At present there are no further plans to develop supporting resources however when the EDAR guidance is due for review this will be a consideration. RCSLT continues to look at options to disseminate information to other professionals involved in a service user’s care.