THE COMMUNIQUÉS

VOLUME 17. ISSUE 4.

Residential Aged Care Communiqué

November 2022 Edition

ISSN 1834-318X

NEXT EDITION
FEBRUARY/2023

Editorial

Welcome to the final Residential Aged Care Communiqué print issue of 2022. Our podcasts will continue to be released over the summer as well as recordings of our Spring Webinar Series. Our team, like most of our subscribers, are looking forward to a well-deserved break and will be back in the New Year.

This edition focuses on deaths from choking and the challenges in making instant decisions about whether or not cardiopulmonary resuscitation should be commenced. The cases present an all-too-common situation that staff in aged care face that could have been better and more easily managed with the relevant and correct information.

The cases highlight the value of knowledge, information about what the resident desires in an emergency situation and understanding the role and limits of the guardians from the public advocate. The title of the first case *'Unknown, unknowable and cannot be known'* is not intended to confuse, rather it highlights an uncomfortable state of knowledge when we must decide about whether to implement emergency treatment. It is worth reflecting on how and when we seek information that could impact on the clinical care of a resident and comparing this to the preferred state of affairs.

Information that remains unknown occurs because we fail to ask or have the uncomfortable conversations when the resident is cognitively capable and able to answer difficult questions for themselves. We tend to forgo having these conversations early believing that later on, when the time comes for a decision, the resident will still be able to answer.

Information that is unknowable occurs when we fail to take an interest in the resident, their life, and their values. Gathering information about a person directly and from their family and friends is invaluable to help interpret what is the most likely preference when the resident cannot express their wishes.

If we are facing a situation where the necessary information cannot be known, we ought to reflect how did this occur. The situation arises when we have failed to talk to the resident, their family, and friends in the past and none of these parties are able to express or available at the time of the emergency.

Our expert commentaries are provided by Kerrie Shiell, a neuropsychologist who addresses issues around impact of dementia on eating. While Julie Cichero, a speech pathologist, examines the complexities in decision-making when care involves a person with dementia, a Guardianship order and whether to commence cardiopulmonary resuscitation when a potentially preventable incident, that is choking causes death.

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The Residential Age Care Communiqué is distributed by the not for profit group 'The Communiques Australia Inc'. (COI--A0106775D)

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FEEDBACK

The editorial team is keen to receive feedback about this communication especially in relation to changes in practice. Please contact us at: **racc@thecommuniques.com**

Case #1 Unknown, unknowable and cannot be known

Case Number Ref No: 39/15 (WA)
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i. Clinical Summary

Mr W was an 84 year old man of English extraction who had lived with a diagnosis of dementia for eight years. Past medical history included hypertension, peptic ulcer disease, osteoarthritis, and prostate cancer.

About five years after being diagnosed with dementia, a transurethral resection of the prostate was proposed to improve bladder and kidney function. As Mr W was not capable of providing consent and had no immediate family or legally appointed medical decision maker, the State Administrative Tribunal appointed the Public Advocate. The order was for a limited capacity to make decisions about the proposed treatment.

Although Mr W recovered well from surgery, he became more dependent in his activities of daily living and transitioned from the hospital into a dementia specific unit of a residential aged care facility.

The Public Advocate's limited guardianship of Mr W was extended for a further five years.

The Guardian appointed noted that Mr W had increasing confusion and decreased mobility with a need for greater assistance. Over the next two years there was further deteriorations in his working memory. Mr W's general practitioner had noted that he was at a high risk of falls, aspiration, infection (urinary and chest) and behavioural problems associated with dementia.

One morning, about three years after entering the residential aged care facility, Mr W was served breakfast. At 0850 hours the carer observed Mr W choking and immediately delivered several blows to his back. The carer inserted two fingers into his mouth but was unable to remove any food.

The registered nurse (RN) was contacted and arrived within moments. The RN struck Mr W's back several more times then attempted to remove the blockage with a suction catheter "yanker" via his throat and nostril, but this only returned a dry suction. At this time, Mr W's blood pressure measured 119/77mmHg and his pulse was 86 beats per minute. He then became less responsive, which prompted a call for the ambulance.

The ambulance received a telephone call at 0853hours and was dispatched promptly. Paramedics arrived at the scene at 0908 hours to find Mr W in the right lateral position, he had no pulse, no breath sounds, and fixed dilated pupils.

> **"Post-mortem examination revealed complete occlusion of the large airways by *'pieces of softened pale-yellow material up to 50 mm in length'*."**

His electrocardiogram (ECG) showed asystole in all leads, and he was declared dead at 0910 hours.

ii. Pathology

Post-mortem examination revealed complete occlusion of the large airways by *'pieces of softened pale-yellow material up to 50 mm in length'*. There was also noted narrowing of one of the vessels supplying blood to the heart and evidence of emphysema of the lungs. Mr W's cause of death was *'upper airway obstruction in a man with a clinical history of dementia'*.

iii. Investigation

Mr W's death was initially reported to the Coroner's Court under the assumption this was a death of a person *'held in care'*. Although Mr W was under a Guardianship order this did not qualify as a person *'held in care'* as defined by the Act and an inquest into his death was not mandated.

An inquest was considered desirable and proceeded with a focus on the appropriateness of the food provided to Mr W prior to his choking episode, whether CPR was indicated and if so, whether it would have prevented his death.

Statements were sought from carers, RN and paramedic involved in the incident as well as other employees and management of the residential aged care facility. The Public Advocate and Mr W's general practitioner also provided statements. Two sources of expert opinions were also considered in this inquest, from specialist physicians in geriatric medicine and paramedic science.

With respect to the choking incident the medical records from the facility revealed a swallowing assessment was performed in the previous year which determined that Mr W required a soft diet. A subsequent entry on his care plan that specified he could have toast without the crust. The medical assessment by his general practitioner noted Mr W *'has a soft diet due to no teeth'*.

The carer who attended to Mr W the morning of the incident was aware that he was on a soft diet and that he often had *'softened toast'* which was described as bread lightly toasted with the crusts off, softened with marmalade or butter and cut into small pieces.

Determining whether CPR was indicated was a much more complex matter with competing opinions.

It was not possible to establish what Mr W would have wanted. Recall he when he entered residential aged care facility, he did not have an advance care directive, nor did he have capacity to create one. His wishes regarding healthcare treatment, including resuscitation, were not known, recorded, or discussed with family.

The Public Advocate who was appointed as Mr W's guardian gave evidence that she, personally or through her delegate, was able to provide or withhold consent for medical treatment based upon the existing circumstances, including the treating doctor's recommendation and the known wishes of the person. However, it was not her role to make an advance health directive on his behalf or to give advance instruction on resuscitation in anticipation of a future critical event. The Public Advocate stated that while her Office was contactable at any time, in emergency situations, health professionals can provide urgent treatment without need to consult with the Guardian, as was the case in this scenario.

The RN had worked for the facility for nine years and her understanding was that CPR was not performed. The RN explained there was not any equipment (e.g., masks to prevent cross infection when performing mouth-to-mouth) to do so. In the event of a resident becoming unwell, the procedure is to call a doctor or an ambulance, as the situation dictated. The RN did not consider that chest compressions alone would have been beneficial and that they would be risky for a frail and aged man.

The care staff believed that the reason for not performing CPR on Mr W was that he was *'not for resuscitation'* due to his underlying diagnosis dementia, age, and quality of life. The aged care facility manager stated that all clinical and care staff had first aid training, that they were expected to administer care consistent with their level of training and roles. The facility did not have a current policy that permits staff to administer CPR.

Another aged care facility staff member with a role in clinical governance and policy for the facility, clarified that CPR was not part of the first aid training for nurses and care staff. Practice at the time of the incident was that any clinical decision to provide life-sustaining care including CPR, rested with the attending RN. This assumed that the RN would know the residents well or be assisted by information from care staff or individualised and comprehensive care plan.

The paramedic who attended the incident gave evidence that he would have recommended and performed CPR. He believed that if compressions (without breaths) had been commenced this would still have been effective and enabled the paramedics to provide more effective treatment. These views were supported by the expert in resuscitation and emergency medicine who described an opt-out model for CPR.

This expert opined that in the absence of the patient's wishes being known, CPR should be commenced and continued until there is clarification to the contrary, a return of a pulse or the situation is deemed hopeless.

The expert considered that an experienced nurse in a residential aged care facility would have the knowledge to assess whether the situation was a potentially reversible emergency. The expert considered that good resuscitation outcomes may be achieved in the aged care setting and explained that in the circumstance of choking CPR would be commenced in the absence of normal breathing.

The expert physicians in geriatric medicine were more inclined towards but did not advocate for an opt-in model for CPR. That is a policy whereby residents would not be resuscitated unless they had previously recorded a wish to that effect in the residential aged care setting. The possible adverse consequences of chest compressions on an older person who is successfully resuscitated included fractured ribs, difficulties breathing, risk of pneumonia, metabolic consequences of the kidney and liver, and heart arrhythmias.

All experts agreed that if the resident's wishes are unknown, the decision concerning whether to perform CPR should be left to the properly qualified staff member, the RN in this case.

iv. Coroner's Finding

The coroner was satisfied that at the time of the incident:

- Mr W did not have an issue with swallowing, but a problem with chewing due to the absence of teeth. Mr W was properly reviewed for his dietary requirements and his carers were aware of these needs. The food provided on the morning in question was appropriate and the airway obstruction was not avoidable.
- The Public Advocate did not have a role in the decisions concerning Mr W's healthcare treatment in the absence of a health directive or palliative care plan.
- The RN involved had the experience and expertise to make the decision not to perform CPR.
- Significant medical intervention would have been required to reverse the airway occlusion and could not have been provided by the staff at that time.
- Administration of CPR would have been unlikely to reverse the occlusion of Mr W's upper airways.

The coroner concluded that Mr W's death was an unavoidable incident and administration of CPR would likely have been futile.

The coroner encouraged the formulation of guidance on the administration of CPR in the aged care setting where the patient has not made an advanced health directive and/or the patient's wishes are not known.

v. Author Comments

Dementia, a progressive and life-limiting condition, is the second leading cause of death in Australia. Proactive discussions about values and wishes are useful to guide future treatment and avoid burdensome interventions or inappropriate care at the end of life. Advance Care Planning alleviates significant stress, anxiety, and depression for family members of those who have died.

For Mr W, whose wishes are unknown, unknowable and cannot be known, who will take on the responsibility of thinking of his future when he is unable to do so?

Few would disagree about the trajectory of Mr W's illness in the months to years leading up to his death. Yet, there was no formulated consensus about his goals of care and resuscitation until this critical incident. This diffusion of responsibility such that *'when everyone is responsible, no one is responsible'*, rarely results in best care and often leaves lingering doubts for those who remain.

vi. Resources

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vii. Keywords

Dementia; Goals of Care; Resuscitation; Choking

Case #2 We did our best: revisited

Case Number 0792/2015
Case Précis Author
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First published in Residential Aged Care Communiqué Feb 2020

Mr S was a 68 year old male with Korsakoff's syndrome (alcohol-related dementia) who had been relocated on several occasions eventually being accommodated in a high-level secure area of an aged care facility that provided constant care and supervision.

One evening Mr S was served an evening meal of soup, sausages, and vegetables. These had been cut into pieces the size of 10-cent coins. Staff noticed he was stuffing food in his mouth and reminded him to slow down. They also removed his plate so he could not continue eating.

Soon after, he collapsed. Staff initiated appropriate first aid measures, including attempts to dislodge food from his throat with back blows. These were unsuccessful and so they commenced cardiopulmonary resuscitation until the arrival of ambulance crew.

When the paramedics arrived a large bolus of food was removed from his airway, he was intubated and transferred to hospital.

Mr S had another cardiac arrest and died.

The cause of death was obstruction of airways by foodstuffs with contributing alcohol-related dementia.

The coroner obtained statements from the aged care facility staff. The statements revealed that staff had noticed a deterioration in Mr S's eating habits, including not chewing his food prior to swallowing and placing too much food in his mouth. The speech pathologist determined that these issues were due to cognitive impairment.

The aged care facility nursing staff had completed a short functional assessment which included advice on Mr S's diet recommending soft textured food cut into bite-size or smaller pieces; one-on-one supervision during mealtimes to prompt Mr S to chew before swallowing and staff to regularly check his room for any evidence of food (given the history of hoarding).

The coroner did not find any fault with the management of Mr S.

Impact of dementia on eating

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The ability to self-feed is crucial to maintaining one's independence. The cognitive and physical changes which accompany dementia are often associated with changed eating ability, higher levels of malnutrition, and increased burden on caregivers. A variety of eating disorders have been described in this population, such as eating inedible objects, significantly reduced or increased food intake and changes to food preferences.

Disorders of eating may be multifactorial in nature, stemming from a raft of cognitive, physical, social, and environmental factors. From a cognitive perspective, executive dysfunction (e.g., apathy, poor initiation and reduced impulse control) alters a person's drive to eat and their ability to regulate eating behaviour. In this context, an impaired ability to regulate behaviour may manifest as gorging food, a preference for sweet foods or obsessive food choices. These symptoms are commonly associated with dementia involving the frontal lobe, such as behavioural variant frontotemporal dementia but can also occur in other subtypes.

Memory impairment has a profound impact on a person's ability to keep track of eating throughout the day, with people often forgetting to eat or forgetting they have already eaten. In the earlier stages of the disease, worsening memory, combined with changes in planning and organisational function, rob a person of their ability to recall the details of old recipes, purchase necessary ingredients or work through the steps required to complete more complex meals.

"As dementia progresses, motor changes often become more apparent, with visual impairment and difficulties with both fine and gross motor skills commonly reported."

As dementia progresses, motor changes often become more apparent, with visual impairment and difficulties with both fine and gross motor skills commonly reported. Changes in a person's ability to pick up subtle contrast between colours is frequently associated with falls and way-finding difficulties, however in this context food intake may be reduced by poor differentiation between the colours of the plate, the table, and the food or when food is poorly presented.

Additionally motor disturbance impacts upon one's capacity to effectively manipulate utensils or open packaged food products.

Perhaps the biggest risk of all focuses upon one's ability to effectively bite, chew or swallow their food. This is an area best assessed by skilled speech pathologists.

Eating is a social activity by nature, with dinner occurring in busy, noisy dining room environments with multiple people. These occasions present as potentially complex and overwhelming for a person with dementia, who is now required to muster additional resources to navigate the cognitive, social, and physical aspects of eating. Despite this, research has shown that food intake increases when mealtimes occur in home-like communal environments.

Disordered eating in dementia is a far more complex issue than most people appreciate. If we are to maintain or improve a person's eating abilities, it will be crucial to undertake a thorough and thoughtful assessment with specialist allied health support to assess and create multi-domain interventions.

A range of strategies to consider:

- Presenting colourful, attractive meals using different coloured plates or placements to improve the contrast of colours.
- Setting up the table, so utensils are already in place rather than contained in packaging.
- Utilising modified utensils to compensate for motor difficulties.
- Using fresh, naturally sweetened foods and vegetable oils to enhance taste in people with changed food preferences.
- Presenting food in two parts for people with apathy or for people prone to gorging food.
- Eating dinner in home-like environments with natural lighting.
- Using nutritional finger food or utilising familiar recipes.
- Maintaining long-standing routines regarding the timing and type of foods.
- Eating is a social exercise, so sitting and engaging with people may also improve food intake.

The cognitive and physical changes which accompany dementia have a substantive impact on a resident's ability to eat and their nutritional state. If staff are made aware of these changes and encouraged to implement from a range of different strategies the care burden reduces with an improved quality of life for residents.

Resuscitation: lessons involving persons with dementia, guardianship and choking

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It's complicated

It is complicated when the person has dementia and is not following instructions to slow down while eating. It is complicated when the person doesn't have an advanced health care directive in place or is under a Guardianship order. It is complicated that the lack of a resuscitation trolley somehow suggests we do the bare minimum. It is complicated that there is currently no national approach to management of choking in aged care.

Choking

Choking presents as the second highest cause of **preventable** death in aged care facilities.[1] It's time to address the "complications" to avoid preventable death by choking. Although choking risk is well recognised in young children, it is not as well recognised that the incidence of choking on food is seven times greater for people over the age of 65 years than it is for children aged 1 to 4 years.[2]

The Australian Institute of Health and Welfare (2019-2020) reported that 80% of choking deaths and 36% of choking episodes leading to hospitalisations were for people over 65 years of age.[3] Older males have a significantly higher choking risk than older females, and there are higher levels of hospitalisation for adults with choking incidents in remote and outer regional locations.[3]

The coronial inquests into the deaths of Mr W and Mr S provide valuable insights. Both men were diagnosed with dementia which limits their ability to communicate and to understand and follow instructions. While care staff instructed Mr S to slow down his rate of eating, it was not until he had already over filled his mouth that the plate was removed. By the time the plate was out of reach, Mr S had placed too much food in his mouth, and swallowed multiple poorly chewed boluses, resulting in food lodgement in his throat and airway.

Encourage care staff to couple their words with gestures to indicate the person should slow down their eating. Remove the plate until you have seen the current mouthful chewed and swallowed before allowing the person to take more food. Watch the larynx rise and fall as an indicator that the person has swallowed. Listen carefully for changes in breathing. Early warning signs of choking include breathing that becomes fast, gurgled, or starts to sound harsh or strained. Imminent signs of choking include loss of voice, agitation, and gasping.

How do we decide whether to resuscitate a resident in an aged care facility?

The coroners' findings showed two different approaches on 'decision to resuscitate' for people who were under Guardianship orders. The detailed report into Mr W's death shows the complexities associated with Guardianship Orders where there is a Public Advocate in place. Under these circumstances the Guardian can provide or withhold consent based on the existing circumstances, but not potential medical events, such as acute choking. In an acute event such as choking, health practitioners can provide urgent treatment without consulting the public advocate.

For Mr W, back blows and suction were used but when these failed the nurse decided not to commence cardiopulmonary resuscitation

(CPR) because of concerns about breaking frail ribs, the lack of mask for rescue breaths, and poor quality of life if rescued. The ambulance was called, and death was accepted as the most likely outcome. For Mr S, CPR occurred, and oxygen was applied until the ambulance arrived, allowing transport to hospital where Mr S later died.

A nationally consistent approach

In order to avoid the diverse reactions seen in the two cases presented, a nationally consistent approach to management of choking in aged care is recommended. Some guidance is provided by the Australian Resuscitation Council, (Guideline 4 Airway Management) and can be applied to all who need airway management. It can be used by bystanders, first aiders, first responders and health professionals.[4] Note, that location of a choking incident or age of the person does not matter. Airway management can and should be applied whenever and wherever it is needed. Back blows and chest thrusts are effective for relieving foreign body airway obstruction with *low risk of harm*. Chest thrusts are similar to chest compressions but delivered sharply and at a slow rate.[4]

Chewing, swallowing assessments and food size

Finally, chewing, and swallowing assessment and awareness of food size and shape that increases choking risk are critical. There appears to be confusion that poor oral preparation of food, often relating to dementia, is not the domain of the speech pathologist. How food is prepared and presented is an important role for speech pathologists to assess and provide guidance.

Dysphagia can occur in the oral, pharyngeal, or oesophageal phases. Speech pathologists must remember that poor chewing skills, for whatever reason, will result in a poorly prepared bolus that may then impact the pharyngeal phase. Cognition, self-regulation and chewing skills should all be assessed by the speech pathologist in determining recommendations for food texture.[5] While many nurses screen for chewing and swallowing difficulties, it is highly recommended they are supported by a speech pathologist when assessing these skills and in determining food texture and drink thickness requirements.

The size of food pieces is critical to reducing choking risk for at-risk individuals. Mr S was provided with food 'cut to the size of a 10-cent piece'. A 10 cent piece measures 22mm in diameter. The International Dysphagia Diet Standardisation Initiative framework, formally used in Australia since 2019, recommends food pieces no larger than 15mm x15mm (Level 6, Soft & Bite-Sized) to reduce choking risk as the food should be small enough to enter the trachea without occluding it.[6] Further, round shapes (e.g., sausage) and certain food textures (e.g., bread/toast) are well known choking risks and should not be provided to at-risk individuals without significant safe guards.[6,7]

Conclusion

Care of a person with dementia who is at risk of choking is much less complicated by examining each aspect of (i) meal preparation and delivery, (ii) swallowing, (iii) multidisciplinary assessment and care planning and, (iv) provision of first aid. Take a step-by-step approach to improving care.

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Views from our nursing colleagues

- The Registered Nurses (RN) in charge of these situations are potentially being placed in unsupported situations to make significant decisions, with no notice, insufficient training, lack of equipment, and lack of policy and orientation to back them up.

- Although it seems these staff are only provided "First Aid Training" and not expected to undertake CPR, there is every chance that in these facilities CPR may be required. This could even be in a situation where a staff member collapses and requires CPR. We would want to be prepared to manage this.

- Whilst an RN may usually know the patient, often casual staff are used and put in charge. How do we ensure they are orientated and aware of the facilities guidance on managing these situations. Are they even clear on the address to call the ambulance to, if new to the facility when placed under pressure.

- The last swallowing assessment was in the previous year. Are they rescheduled to reoccur again at certain intervals proactively given that it may take some time to get a new appointment once a new issue is recognised.

- Experts have opinions, but the poor nurse is left with the weight of the world on her shoulders, not only as the incident is occurring, but afterwards. We should know what to do in these situations, and each resident should have a clear patient centred plan to guide staff on what to do. This should be proactive. Supporting the workforce on the ground is not negotiable, its essential to keep them coming back to work.

- My gut feeling is it is good to concentrate on the role of the Public Advocate and how it may be different to when a family member is the legal decision-maker.

- It would be worthwhile for staff to identify the residents who have a public advocate and to understand exactly what that means in terms of the decisions that can be made.

- Finally, understanding how often are end of life care plans discussed and reviewed in your aged care facility and what prompts an earlier review.

List of Resources

1. Residential Aged Care Communiqué Vol 15 Iss 1 Feb 2020. Available at: https://www.thecommuniques.com/post/residential-aged-care-communiqu%C3%A9-volume-15-issue-1-february-2020.

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Acknowledgements

This initiative has been made possible by the voluntary contributions of the authors and editors in collaboration with 'The Communiques Australia Inc'.