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**OFFICE OF THE PUBLIC ADVOCATE**

**DYSPHAGIA POSITION PAPER**

**1. PURPOSE**

The South Australian Office of the Public Advocate (OPA) has responded to requests from the health sector to write a position paper about dysphagia management following the dysphagia colloquium held in February 2003.

The contents of, and advice in, this paper are the opinion of the Office of the Public Advocate only, and individuals should not act without first consulting with their risk managers. However, the paper may assist risk managers in developing appropriate policies and protocols that reflect the complexities of dysphagia management and the need to view the immediate and life threatening risks as one aspect of the decision making process.

**2. HISTORY**

The Packer Coronial Inquiry in 1993 (which will be expanded upon in more detail later in this paper) has set the scene in South Australia for the Crown Solicitor's Office to provide a consistent opinion on consecutive occasions regarding the legal ramifications associated with dysphagia management. The crux of the opinion is that health services, in developing policies for dysphagia management, should not sanction the provision of food or fluids that are not in accordance with medical advice even with the patient's informed consent. This was certainly the case in 1996 when the Public Advocate at the time, John Dawes, sought a Crown Law opinion in order to provide advice to facilities caring for people suffering with dysphagia, particularly regarding mentally incapacitated dysphagia patients. He had been approached by medical staff at the Julia Farr Centre concerned about the focus on litigation in policy decision making regarding dysphagia management, and how such policies were seemingly adversely impacting on people's autonomy.

The Crown Law advice stated that, given it could amount to assisted suicide (ie murder or manslaughter) to do so, where there is an immediate and life threatening risk to the patient, it is appropriate for residential health facilities to refuse:

- to provide food that is not in accordance with medical advice; and
- to supervise in a non-negligent manner the consumption of such food on their premises or whilst the patient is in the care of a staff member.

The advice included the opinion that if a patient is determined to eat food that is not recommended by the medical practitioners, the patient not be allowed to place staff or the facility at risk of committing a criminal offence.

In 1999, the Department of Human Services (DHS) also sought a Crown Law opinion in response to questions from Flinders Medical Centre leading to the advice that, even with the patient's informed consent, the health service should not supply food or fluids deemed inappropriate by the clinicians.

In 2002, John Harley, the current Public Advocate, was contacted by senior staff at the Repatriation General Hospital to discuss the practical difficulties they were having implementing the principles expounded in the Crown Law advice. It was decided that the Public Advocate would convene a colloquium with all relevant parties to:

- discuss the legal, medical and ethical issues involved in the dilemmas of dysphagia management for clinical staff and clinical institutions; and to
- provide a basis for 'best practice' of dysphagia management within the bounds of the areas of discussion.

### 3. THE OPA POSITION ON DYSPHAGIA

Ingrid Norman, Managing Solicitor, Crown Solicitor's Office, outposted to the Department of Human Services, pointed out that the legal advice referred to above was predicated on there being an immediate and life threatening risk to the patient/client. It is the Office of the Public Advocate's view that the legal advice is based on extreme circumstances and Ingrid Norman acknowledges that there is clearly a range of clinical circumstances to be considered to assess whether individual cases fall into that category of risk. Professor David Currow, Chair of Palliative and Supportive Services at the Flinders University of SA and Director of the International Institute of Hospice Studies and Southern Adelaide Palliative Care, expanded on this crucial element by pointing out that risks for patients with dysphagia vary greatly and are relative not absolute. One patient may aspirate, he says, but there may be no respiratory compromise experienced and the consequences may be well tolerated while another patient may tolerate the consequences poorly.

A vital factor, which did not seem to be addressed in the advice given by Crown Law, is that it is not just the giving of solid foods that is the cause of extreme risk for patients with dysphagia. In the Packer case, Mrs Packer was a dysphagia patient with a mental incapacity who medical staff deemed required a soft diet. On the occasion leading to her death she was given a sausage roll meal as per the meal plan prepared by a pantry maid, not by nursing staff, as procedure dictated. The Coroner, Garth Thompson, noted in his findings in 1993 that the pantry maid gave the meal *probably with the consent of Mrs Packer*. Only half of the sausage roll was cut into smaller pieces and Mrs Packer was not supervised while eating. When it was discovered she was choking, the nurse on duty followed the appropriate procedures, including organising the resuscitation team to be summoned. A series of mishaps occurred in the summoning process, which the Coroner reported *in themselves would not have been fatal but taken cumulatively were fatal*. The Coroner concluded in his findings that *the Julia Farr Centre on this occasion failed:*

- *in properly supervising the meal collection;*
- *in properly supervising the meal consumption; and*
- *in properly summoning both the resuscitation team and ambulance.*

The patient died not just because of eating solid food, but also because of other negligent behaviour in the hospital. If Mrs Packer's other half of the sausage roll had

been cut up into smaller pieces she may not have choked, equally she may have survived if she had been supervised while eating. The legal advice emphasises the liability risks relating to the immediate risks in the giving of solid foods, without consideration of all the aspects of care including:

- those that may place any patient at risk such as inappropriate staffing levels or poorly trained staff; and
- consideration of each individual patient's health status and needs, which vary greatly as Professor Currow so clearly outlines.

Clinical managers therefore should not interpret the Crown Law advice in an exclusive manner, emphasising the risk of criminal prosecution. What is required in the overall planning of dysphagia management is the ongoing consideration of the complexities of each individual case and the environment that cares for them. This can occur through thorough, multi-disciplinary examination determining each patient's clinical risk factors, and through ongoing open communication with the patient or the patient's representative or guardian, the family members and the clinical team. According to Professor Currow, judging risk is a multi factorial continuum and all the parties involved in the dysphagia management need to consider the benefits versus the burden in the decision making process.

#### **4. ROLE OF THE SUBSTITUTE DECISION MAKER IN RELATION TO PEOPLE WITH DYSPHAGIA WHO HAVE A MENTAL INCAPACITY**

The substitute decision maker has the duty to consider the rights of the person with the mental incapacity and to understand the complexities involved in his or her treatment and care. Ongoing consultation with the clinical team caring for the patient, as mentioned above, is crucial in the decision making process.

Proof of the patient's wishes or an advance directive (executed prior to becoming mentally incapacitated) assists the guardian, as substitute decision maker, in making appropriate decisions according to the principles of the *Guardianship and Administration Act 1993*. If proof of wishes is absent and an advance directive does not exist then his or her current wishes must still be a consideration.

#### **Overall the independent decision maker is obliged to:**

1. Examine and understand in consultation with the clinical team:
  - the risks to the protected person regarding aspiration or choking;
  - the risks to the protected person regarding the environment within which they reside;
  - an understanding of the protected person's cultural, social, psychological and spiritual needs; and
  - patient wishes for the level of support in the face of aspiration or choking.
2. Discover whether or not proof of wishes prior to the mental incapacity exists.
3. Discover whether or not an advance directive exists.

It is only then that a reasonable and proper decision may be made with regard to whether or not the protected person is able to access particular foods and fluids.

## **5. BEST PRACTICE**

Best practice must take into consideration both the legal and practical issues in the delivery of service, as well as the rights of the patients and their cultural, social, psychological and spiritual needs. Protocols in health facilities need to reflect these areas of consideration if best practice is to be applied.

Protocols for practice should include examination and documentation of:

- patient issues;
- staff and environmental issues;
- family issues;
- evidence of the patient's wishes;
- evidence of the type of relationship the patient and the patient's family have with clinical staff;
- evidence of effective and informed consent processes in consultation with the patient and the family on an ongoing basis;
- determining the degree of risk and the cause and effect level of predictability;
- working to a consistent interpretation;
- discussing the degree of risk with the patient or the patient representative; and
- defining, reviewing and re-examining the degree of risk on a continual basis in consultation with all the relevant parties.

If economic factors are impinging on the patient's environment at any one time, this must surely also be factored into the decision making process. These realities contribute to the nature and quality of service provision and how well risk is managed.

## **6. CONCLUSION**

Good practice, including assessment of clinical risk, and decisions made in good faith and without negligence with the objective of improving a patient's quality of life, provide some protection for medical and clinical practitioners. Allowing fear of litigation to be the driving force for decision making is at best disrespectful, and at worst neglectful and ethically and morally wrong. While risk of criminal prosecution and or/civil liability must always be considered, it is but one aspect to consider in risk management and the overall delivery of service to patients suffering with dysphagia.

In order to encourage best practice in dysphagia management, hospitals would be advised to ensure that their policies reflect support of staff abiding by the properly documented, adequately assessed consensus decision making, regarding each individual's dysphagia management. By supporting staff in their practice and by encouraging them to constantly be weighing up the rights of the patient versus their safety, a dynamic and just approach, will be ensured in the clinical management of dysphagia patients.

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**1st Edition**  
**December 2003**