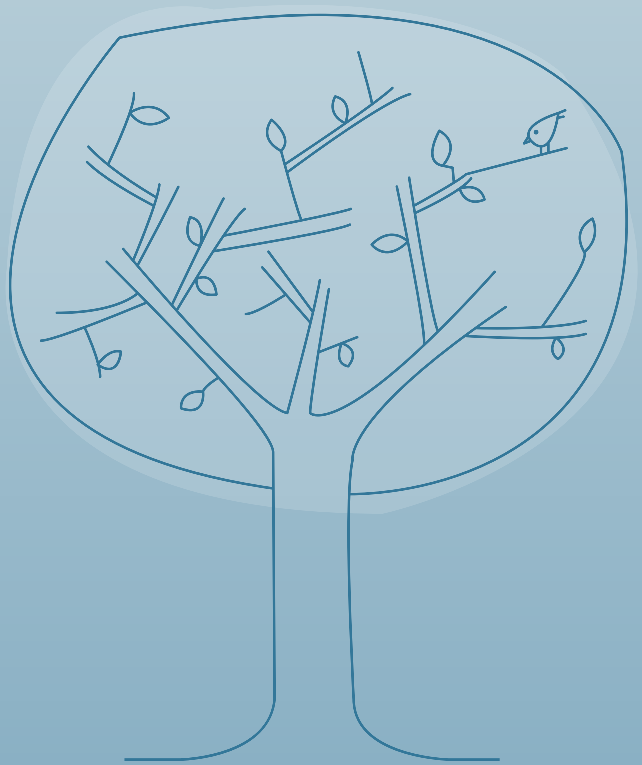
Irish Association for Palliative Care

Position Paper on

# Nutrition and Decision Making in Palliative Care

May 2025



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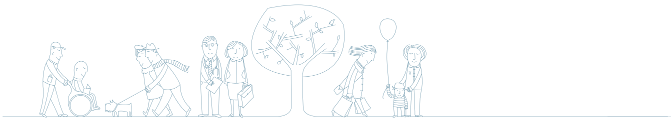
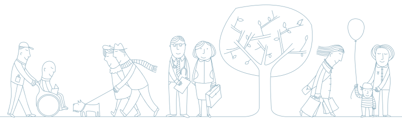


## Contents



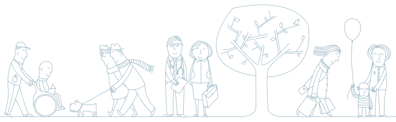
# 1. Executive Summary

Palliative care is a philosophy of care, focused on quality of life, and providing multidisciplinary holistic care to people with life-limiting conditions, and their families. Through the practice of palliative care, care can be provided not just at the end of life but at any stage of a life-limiting condition.

The Irish Association for Palliative Care (IAPC) has put together this position paper, to discuss the use of clinically assisted nutrition (CAN) and why it may or may not be used in caring for people with life-limiting illnesses, including at the end of life.

In this position paper, we explore patient autonomy, supporting a patient's right to make choices, including the right to decline treatment, and to make advance healthcare decisions. We also explore the clinician's responsibility that, while ensuring an individual is comfortable, no decision is made that would cause them harm or create false expectations about the limits of CAN. Due diligence should be given to both the commencement and discontinuation of CAN.

This document represents a consensus view of the IAPC. The views of individuals within the organisation may vary from those in this position paper. This document was produced by the IAPC Ethics Forum which is a multidisciplinary committee drawn from the membership of the IAPC (www.iapc.ie)



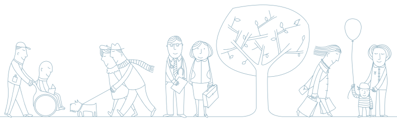
# 2. Glossary

**Clinically Assisted Nutrition/Artificial Nutrition:** Clinically assisted nutrition (CAN) refers to all forms of tube-feeding (via tubes into the gastrointestinal tract or parenteral, intravenous nutrition). It does not cover oral feeding, by cup, spoon or any other method of delivering food or nutritional supplements into a patient's mouth [1] (BMA, 2018).

**Feeding with accepted risk/ Feeding for comfort:** Is feeding for the purpose of taste, sensation, comfort, quality of life and may also be known as comfort feeding [2] (RCSLT, 2021). This may be associated with risks (such as aspiration pneumonia, which is a lung infection resulting from the inhalation of secretions or gastric contents). In choosing this approach the benefits (to provide the patient with comfort and/or satiety) have been deemed to outweigh the risks. This decision should be made alongside the patient and their family.

**IAPC:** Irish Association for Palliative Care

**Palliative Care:** Palliative care is care that improves the quality of life of patients and their families who are facing the problems associated with life-limiting or life-threatening illness. Palliative care prevents and relieves suffering by means of early identification, impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems [3] (World Health Organization, 2015).



## 3. What is palliative care

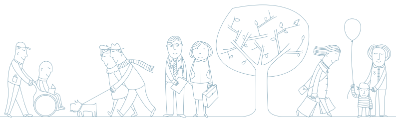
Palliative care is a philosophy of care, providing multidisciplinary, holistic care to people with life-limiting conditions, and their families. It is focused on their quality of life. It seeks at all times to respect the integrity, individuality and unique worth of each person regardless of their ability or functional status. Palliative care is about caring for a person with a life-limiting illness, and to support those significant to them throughout their illness.

Palliative care emphasises good communication between patients and healthcare professionals and promotes the collaborative nature of care. Establishing trust between the patient and the healthcare team is vital so that patients know that their wishes will be respected, even when they are no longer able to voice them.

## 4. Eating is basic care and a human right

Food is a basic need of all human beings. All patients are entitled to appropriate nutrition and the opportunity to enjoy food. It is important to ensure that patients receive assistance from healthcare staff if they need help and wish to eat orally.

If a patient is unable to take sufficient food orally, consideration should be given to provision of nutrition by CAN. This decision should be made by balancing the benefits, burdens and risks of each form of treatment whilst taking the view of the patient and their family into account.



# 5. Initiation of clinically assisted nutrition

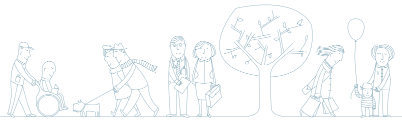
CAN is a medical intervention, requiring an indication, a therapeutic goal and the will (consent) of the competent patient[4]. The emotional and social impact of these decisions on the patient and their family requires careful consideration.

An integral part of the right to consent to medical care is the right to refuse treatment, even if that treatment is life prolonging[5] (Medical Council, 2024). This is NOT equatable to assisted dying.

Doctors are not obliged to initiate or persist with treatments that are disproportionately burdensome to the patient. There is no obligation to start or continue nutrition by medical intervention if a clinician judges that it is:

- Unlikely to work,
- Might cause more harm than benefit,
- Is likely to cause the patient pain, discomfort or distress that will outweigh the benefits it may bring[5] (Irish Medical Council, 2024).

If it is deemed that CAN will not be of overall benefit to the patient, the patient should be kept as comfortable as possible and their symptoms addressed. Where possible, the patient and/or those close to them should be told of the decision and the reasons for it.



# 6. Making decisions/decision making, capacity and advance healthcare directives

Autonomy refers to the right of decisionally capable adults to make decisions regarding their healthcare. The intent of this ethical principle is that there is respect for the person's preferences, that the person is fully informed of the healthcare options, and that the individual is involved in decision-making.[6] The IAPC endorses the right of the competent, informed patient to decline medical treatment, even if this leads to their death.

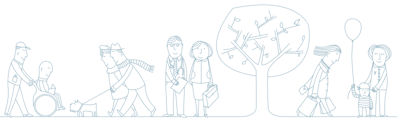
All patients are presumed to have decision-making capacity. If there are any doubts about this, competency to make decisions can be assessed by one or more clinicians. The situation is more complex when an individual patient is unable to make decisions regarding their treatment options independently. The Assisted Decision Making Act supports decision-making and aims to maximise a person's capacity in order to help uphold their rights and safeguard their autonomy.[7],[8] Where patients have written an advance healthcare directive, and the decision covers the situation that has arisen, then the advance healthcare directive should be followed, in line with Irish Medical Council guidelines and the Assisted Decision Making (Capacity) legislation.[7],[8]

An advance healthcare directive has the same ethical status as a decision made by a patient at the actual time of an illness and should be respected on condition that it was:

- An informed choice
- The decision covers the situation that has arisen
- There is nothing to indicate that the patient has changed their mind [5] (Irish Medical Council, 2024).

CAN is defined as a medical treatment [4] and medical treatments can be declined via an advance healthcare directive if the life-sustaining nature of the treatment is clearly stated. Life-sustaining treatment includes any clinically appropriate medical treatment, technology, procedure, or medication that is administered to preserve life and which, if not provided, would result in a significant risk of death.

In situations where no advance healthcare directive exists and a person requires assistance in exercising their decision-making capacity, decisions should be made in accordance with the person's will and preference, in conjunction with any decision-making supports that may be in place in keeping with the Assisted Decision Making (Capacity) legislation.[7],[8]



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## 7. Discontinuation of clinically assisted nutrition

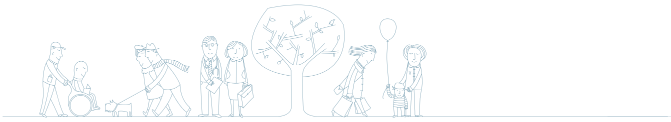
Discontinuation of CAN is a measured decision, made when this medical intervention is deemed no longer beneficial and/or will not enhance the patient's quality of life and/or continuation involves intolerable suffering/discomfort/distress for the person. It is a decision made alongside the patient and their family. Health care personnel have an obligation to maximise potential benefits for their patients, while, at the same time, minimising potential harm for them.[6] If CAN is discontinued, symptom management and quality of life should continue to be optimised (See Applicant v. Patricia Hickey, Committee of the Ward and Health Service Executive Respondents (2021)).[9]

## 8. Eating and drinking with acknowledged risk/comfort feeding

"Eating and drinking with acknowledged risk" or "comfort feeding" refers to the decision to continue eating and drinking orally despite the associated risks from having problems swallowing. One risk is that of aspiration pneumonia, which is a lung infection resulting from the inhalation of secretions or gastric contents. The risks should be acknowledged and a plan made to manage anticipated adverse events should they arise. Eating and drinking with acknowledged risk is an approach that may afford comfort, dignity and autonomy for patients with an unsafe swallow, where no safe and acceptable method of eating and drinking has been established, and where CAN is unsuitable.[10] Risk minimisation should occur, with regards to consistency of food, positioning, timing and potential fatigue.

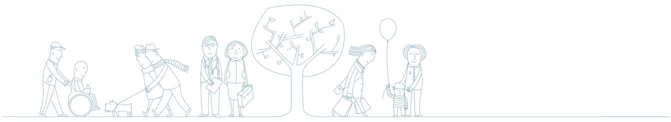
## 9. Feeding at end of life

A reduction in a person's oral intake of food is an expected part of the natural dying process. As a person approaches the end of their life, the administration of food becomes less necessary.[6] The administration of CAN in the dying phase (a time of life which is naturally associated with a reduction in levels of consciousness carries risks and burden and does not serve to promote or preserve the length or quality of a person's life.[11]



# 10. Conclusion

The IAPC has put together this position paper, to discuss the use of CAN and why it may or may not be used in caring for people with life-limiting illnesses including at the end of life. It is the clinician's responsibility to support a patient's right to make choices, including the right to decline treatment, and to make advance healthcare decisions. Initiation, continuation and discontinuation of CAN should be a carefully considered decision made on an individual basis with respect to the patients circumstance, risks and benefits and patient's preferences.



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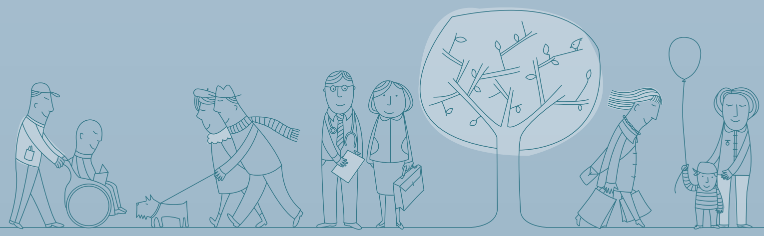

Established in 1993 as an all-island body with the purpose of promoting palliative care nationally and internationally, the Irish Association for Palliative Care (IAPC) is a multidisciplinary membership non-government organisation. The intention of the founders was that IAPC would be identified by its inclusiveness and would encompass the whole island of Ireland.

The IAPC membership reflects the entire spectrum of all those who work in or have a professional interest in the provision of palliative care. This includes doctors, nurses, social workers, chaplains and pastoral carers, pharmacists, psychologists, physiotherapists, occupational therapists, dietitians, speech and language therapist, as well as executive staff, academics and educators. Membership also includes clinicians and allied health professionals working in related areas such as geriatrics, oncology, psycho-oncology, paediatrics, and pain management.

The IAPC is organised around a number of working groups designed to create forums aimed at promoting best practice, professional development, research and learning in palliative care. education and research.

**Irish Association for Palliative Care**
Carmichael House, 4 Brunswick Street North, Dublin 7 D07RHA8
T: 01 873 4735
F: 01 873 5737
E: info@iapc.ie

**www.iapc.ie** for more information and on-line membership application