

International Children's Palliative Care Network (ICPCN) Position Statement on the Practice of Euthanasia and Assisted Suicide

Purpose	To state the position of ICPCN on euthanasia and assisted dying to support members engaged in discussions in their countries.
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Summary	This statement clarifies the position of ICPCN on euthanasia and assisted death.
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Introduction

The International Children's Palliative Care Network (ICPCN) is a network of individuals and organisations working in children's palliative care worldwide. The vision of ICPCN is to live in a world where every child and young person with a life-limiting or life-threatening condition and their families can receive the best quality of life and care regardless of which country they live in. We believe that the total needs of life limited and life threatened children should be met to encompass physical, emotional, spiritual and developmental aspects of care. To achieve this, children's palliative care must be acknowledged as a unique and specialist service.

ICPCN aims to:

- Assist services across the world to develop and meet the total care and support needs of life-limited children and their families.
- Advocate for and raise awareness of children's palliative care and the specific needs of life-limited or life-threatened children and their families.
- Campaign for the global development of children's palliative care services.
- Increase the international evidence base for children's palliative care.

Definitions

Palliative Care is defined by the World Health Organization as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spirit; it

- Regards dying as a normal process;
- Focuses on the quality of living as death approaches;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Enhances quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life and includes those investigations needed to better understand and manage distressing clinical complications.

The goal of palliative care is to relieve suffering and improve quality of life.

Euthanasia is the deliberate act of intentionally, knowingly and directly causing the death of a patient, at the request of the patient, with the intention of relieving intractable suffering. If someone other than the person who dies performs the last act, euthanasia has occurred.

Euthanasia can be:

- a) Voluntary where a competent person requests it.
- b) Involuntary where a competent person is not consulted
- c) Non-voluntary where the person is not competent to make the request

The term 'voluntary' alone does not imply the decision is an autonomous one, since competent people may be subject to various forms of coercion (deliberate or otherwise).

Physician Assisted Suicide is the act of intentionally, knowingly and directly providing the means of death to another person, at the request of the person, with the intention of relieving intractable suffering, in order that that person can use that means to commit suicide. If the person who dies performs the last act, assisted suicide has occurred

Palliative Sedation is the monitored use of medications intended to induce a state of decreased or absent awareness in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and health care providers.

None of the following should be seen as euthanasia

- Withholding treatment that will do more harm than good.
- Withdrawing treatment that will do more harm than good.
- Sedation that is necessary for relief of distress caused by refractory symptoms.

No medical intervention is permissible unless its benefits outweigh its harms. When cure is no longer possible, those benefits and harms must be considered broadly in a way that includes emotional, psychological and spiritual interests as well as physical. Since it is the

child's family who know them best, such consideration relies on discussions between the family and health care team (and where possible, the child themself) to establish whether interventions are on balance, and considered in that broad way, in the child's best interests. Interventions that are not in the child's best interest – that is, whose harm outweighs benefits – should be withdrawn or withheld. That represents ethically sound clinical decision-making and does not constitute any form of euthanasia.

Position Statement

The aim of children's palliative care is to enable the child to live a life of maximum quality possible by preventing and relieving suffering. Enabling good quality of life cannot include hastening death, and we do not believe that euthanasia or physician-assisted suicide is part of children's palliative care.

The ICPCN acknowledges that even with the best support palliative care can offer, the suffering of children and their families may not be relieved at all times.

The ICPCN acknowledges the significant deficits in providing palliative care for children with life-limiting and life-threatening conditions around the world.

The ICPCN advocates for healthcare reform programmes around the world to strengthen end of life care by remedying shortages in the palliative care workforce and ensuring access to appropriate medications and resources.

Good practice requires that the ethical principles of beneficence and non-maleficence should be followed at all times. Medical interventions are only permissible when their benefit to the patient outweighs their harm. Withholding or withdrawing interventions causing more harm than benefit does not constitute euthanasia.

The unintended death of a child as a consequence of an appropriately prescribed intervention to provide comfort for a distressing symptom, even when death is a possible outcome from the intervention, is not euthanasia. Sedation that becomes necessary for management of distress caused by refractory symptoms ('palliative sedation') is not euthanasia.

Many requests for euthanasia or physician assisted death are made in order to draw attention to specific causes of emotional distress and despair. Those can often be reversed with appropriate support. Such requests should be acknowledged with respect and be extensively explored in order to understand, appropriately address and, if possible, remedy the underlying difficulties that gave rise to the request.

In the face of a request for euthanasia or physician assisted death, provision of effective symptom control becomes particularly important, especially with respect to symptoms associated with a serious and sustained "desire for death" such as depressive disorders and poorly controlled pain. In such situations, early referral to an appropriate specialist should be considered.

Recommendations

The ICPCN recommends that all governments:

- Integrate children's palliative care into all levels of their country's health care system.
- Integrate children's palliative care into the curriculum of medical, nursing and allied health workers.
- Encourage advance care planning and discussion of preferences for end-of-life care with children and their families.

References

- 1. Palliative Care Council of New Zealand. The Palliative Care Council of New Zealand's position on Euthanasia. June 2013.
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- 3. Liz Gwyther, Neil Malan, Sarah Fakroodeen. WPCA position paper on euthanasia and assisted dying. The Worldwide Palliative Care Alliance. May, 2013