

# Importance of advanced directives: Description of a complicated case in a palliative care unit

Isabelle Beytrison RN, Caroline Matis RN, Marie Preumont RN, Mireille Balahoczky RN  
Department of Rehabilitation and Geriatrics, Geneva University Hospitals, Geneva, Switzerland  
Correspondence to: marie.preumont@hcuge.ch



## Background

Terminally ill patients often suffer from **physical and psychological distress** despite treatments given by the caregiving staff. Conversely, these circumstances lead to **significant stress** among the caregivers in palliative care (hospice care) units.

## Objectives

The present study is based on the case of a patient in a palliative care unit, whose management was considered complicated and stressful by the caregivers.

The aim of the study is to:

- Determine the reasons for which a **given case is a source of trouble and stress** for the caregivers.
- Review the importance of **advanced directives**.
- Review the indications and applications of **terminal sedation**.

## The Setting

The **Center for Continuing Care (CESCO)** is part of the Department of Rehabilitation and Geriatrics of the Geneva University Hospitals, in Switzerland. It includes 104 beds, and 30% of the patients are admitted for terminal disease-related care. The present study is based on a patient who stayed at the Unit 40, which is a ward for **palliative care** with 13 beds that opened in 1987. It is presently recognized by the World Health Organization as a model for practice, education and research in palliative care.<sup>1</sup> The staff includes 1 attending physician, 1 resident, 1 head-nurse, 8 nurses, 7 assistant-nurses, and paramedical workers.



## Case presentation

The case of a 69-year old male with **end-stage widespread metastatic prostate cancer causing important back pain**, who developed acute worsening of his general status during his stay, leading to the introduction of terminal sedation. He was admitted for adjustment of his analgesic therapy. His stay lasted approximately 3 months:

- Day 1 – day 14: the treatments were efficient, and the **patient was relieved** of his symptoms.
- Day 15 – day 50: his status was fluctuating, with **progressive worsening of his pain and mental confusion**, leading to several adjustments of his treatment.
- Day 51 – day 85: **marked deterioration** of his general status, with severe increase of the pain, leading to an intensification of the analgesic therapy, as well as a palliative surgery (laminectomy). Finally, the pain became intractable. With agreement of the patient's family, **terminal sedation** was therefore started. The patient expired 3 days later.

## Methods

The 10 caregivers (1 attending physician, 4 nurses, and 5 assistant-nurses) who were in charge of the patient were interviewed through **open questionnaires**, 3 months after he expired.

The questions:

1. As a caregiver, was this an easy or a difficult situation? Please describe briefly what you felt.
2. Did the means that were at your disposal to handle this patient seem sufficient?
3. Was there anything missing?
4. What else could have been done?
5. What are your feelings about this case 3 months after the patient expired?

## Results

All the caregivers believed that the situation was **difficult**, because of the numerous changes in the treatment of the patient. The main feeling was **powerlessness and defeat**. They all thought that the patient could have been handled better. The means at their disposal for handling the case were judged as **sufficient, but insufficiently used**. There should also have been a higher degree of **inter-disciplinary communication**, and more frequent meetings among the care givers to reach a **consensus on the attitude** toward the patient. Furthermore, it was felt that the worsening of the patient's status could have been **anticipated**. This could have led to the establishment of **advanced directives** with the patient's family. Another point was that **more attention** could have been given to the patient's **psychological distress** and not only to his **physical pain**. In addition, it was also stated that the intervention of a **specialist from outside the service** may have helped. The feelings stated by the caregivers were a lasting sensation of **defeat, dissatisfaction and disappointment**, as well as **relief** that the patient had expired, and therefore did not suffer more. Many feared going through a similar situation again. There was also the wish to have a **discussion** of the case under supervision.

## Discussion

This case illustrated how difficult a given patient may be difficult to manage, despite all the means at our disposal.

Increasing the amount of medical intervention does not always lead to a better care.

Furthermore, when a situation abruptly worsens, the caregivers may be forced to take emergent **hasty decisions**, with a lack of deep insight into the patient's condition.

It is, therefore, essential to **anticipate any deterioration**, by clearly **establishing advanced directives**, most importantly on issues such as **terminal sedation**, as seen in this particular case.

## Advanced Directives

Provides the opportunity for an individual to document instructions for future medical care.<sup>2</sup> In the event that this individual becomes incompetent or seriously ill and is no longer able to participate in decisions about his medical care, this document serves as a guideline delineating the individual's wishes. They are defined by two broad categories:

- **Instructive directives**, such as a living will: «Have you given any thought for what kinds of treatment you would want (and not want) if you become unable to speak for yourself in the future?»
- **Health care proxy**: «If, with future progression of your illness, you are not able to speak for yourself, who would be able to represent your views and values?»<sup>3</sup>

## Terminal Sedation

Refers to use of a pharmacological agent(s) to **induce unconsciousness** for treatment of truly distressing symptoms in the **terminally ill**.<sup>4</sup> The patient then dies of dehydration, starvation, or some intervening complication. Because patients are deeply sedated during this terminal period, they are believed to be **free of suffering**.<sup>5</sup>

There are several important aspects of terminal sedation which should be determined:

- **How** to approach the issue with the patient?
- **When** is the **best time to talk** about it?
- **At what point** should it be initiated?

Terminal sedation should result from a **consensual decision** taken by the patient with his family and the caregivers. Furthermore, it is important to remember that the aim is to give relief to the patient himself, and not to the family or the caregivers.

In addition, this raises **important ethical issues**, in relation to the boundaries that are sometimes ambiguous between terminal sedation and euthanasia.

## Conclusions

In a palliative care unit, the caregivers are faced with complex cases, which may rapidly and abruptly worsen. Because of the rapidity of the patient's aggravation, the caregivers may have to take hasty decisions, leading to an increased degree of stress.

In order to appropriately manage these kinds of situations, it is important to stand back from the events:

- **«Preventively»** by anticipating a given situation through establishment of **advanced directives** with the patient and his family.
- **«Continuously»** by maintaining **multi-disciplinary communication** in order to achieve a coherent management by the caregiving staff.

## References

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