Medicine of the Person
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Conference ***4***

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Resuscitation status in patients with neurological disease: a symbol of stigma?

Introduction

Decisions surrounding resuscitation status – whether referred to as a ‘do not attempt resuscitation order’ (DNAR) or limitation of active treatment – raise complex questions at the intersection of medicine, ethics and society. In the field of neurological diseases, these decisions take on an even more difficult dimension. Whether it is a question of neurodegenerative diseases, major strokes, traumatic brain injury or advanced neuromuscular diseases, these situations confront doctors and families with difficult questions: what will be the long-term level of consciousness or autonomy? What quality of life can be expected? Is it still right to continue intensive care?

Autonomy remains a core value for many, especially in old age. Furthermore, the prospect of being admitted to an institution, with its implications in terms of loss of autonomy and cost – both human and economic – often weighs heavily. Can we honestly say that these considerations, including the costs to relatives or the community, never, even indirectly, factor into the decision about resuscitation status?

But another, less visible factor deserves to be examined: the role of the emotions and perceptions of the caregiver themselves. Behind some decisions not to resuscitate, there may be more than just strict medical analysis: difficulty imagining oneself in a state of dependence, fear of disability, or simply a form of intolerance to what life can become when it no longer meets standards of autonomy and performance. In such moments, resuscitation status risks reflecting our own limitations as much as the patient's.

Is a decision to be not for resuscitation a symbol of futility of treatment and does it lead to a changed perception of the value of the patient's life?

I. Resuscitation status: definition, principles and practices

A. Definition and regulatory framework

Resuscitation status refers to an advance decision, whether formalised or not, not to perform cardiopulmonary resuscitation (CPR) in the event of cardiac or respiratory arrest. This decision is most often part of a comprehensive approach to limiting or withholding treatment. In Switzerland, this process is based on several legal and ethical foundations. The Swiss Civil Code (Art. 370 to 373 CCS) allows any person with capacity, to draw up advance directives in which they can refuse or accept certain treatments, including resuscitation. These directives may also designate someone to have power of attorney for health. In addition, the medical guidelines of the Swiss Academy of Medical Sciences (SAMW), particularly those relating to end-of-life decisions, provide an ethical framework of reference. They emphasise the importance of respecting the patient's wishes, of care being proportionate and the use of a collegiate process in cases where the patient lacks capacity. Finally, cantonal laws on patients' rights and the ethical principles of the Swiss Medical Association (FMH) also provide a framework for these decisions, emphasising dignity, autonomy and the principle of not insisting on treatment.

B. Current clinical practice

In hospital wards, discussion of resuscitation status is a mandatory step in the admission process. Particularly in the case of elderly patients, patients with multiple pathologies or patients with serious neurological diseases, a discussion on the meaning of cardiopulmonary resuscitation is often initiated either with the patient or with their next of kin. From the moment of admission, the medical file always includes a section on resuscitation status. The resuscitation status is discussed each time the patient is presented during handovers between doctors and nurses. Often, this discussion with the patient is not necessarily conducted by the most experienced doctor on the team, but by the junior doctor who admits the patient. This shortcut in decision-making can be problematic, particularly when it determines how the patient will be managed from the outset. If a hospital does not have a neurologist on call or a neurology department, the decision on resuscitation status is made by a doctor who is not necessarily familiar with the medium- and long-term prognosis of certain neurological diseases. Most non-university hospitals in Switzerland do not have a neurologist on call.

C. Success of CPR: the importance of age and the condition at presentation

The success rates of cardiopulmonary resuscitation vary considerably depending on age, comorbidity and the cause of cardiac arrest. In young, previously healthy patients, the chances of survival with good neurological recovery can exceed 30% (Fuchs 2021). In contrast, in elderly patients, rates of success are very low (< 5%) (Van den Glind 2013). This data should guide, but not dictate, the decision: the approach must remain individualised.

However, clearly, we want to spare a patient a poor prognosis and the trauma of cardiopulmonary resuscitation.

II. Specific features of neurological diseases

A. Diversity of clinical presentations

The field of neurology is vast and heterogeneous: a patient may suffer a massive stroke, traumatic brain injury, amyotrophic lateral sclerosis, encephalitis, or live with progressive multiple sclerosis. Some conditions are reversible, others inevitably progressive. Some diseases occur suddenly and do not allow the patient to express their wishes: the patient develops aphasia after a stroke, or the patient has prolonged post-traumatic confusion. The neurological prognosis is often difficult to establish with certainty, especially in the acute phase.

B. Difficulties in prognosis in acute brain injury

In patients with acute brain injury (head trauma, intracranial haemorrhage, hypoxic brain injury after cardiac arrest), predicting neurological outcome remains particularly challenging. Tools such as the Glasgow Coma Scale (GCS) and the Full Outline of Unresponsiveness (FOUR) are commonly used, but they have significant limitations: they are subjective, they have poor inter-observer reliability and limited prognostic value, especially in intermediate scores (Amujuela 2019). Despite this, excessive reliance on early prognoses can lead to early withdrawal of care (Minhas 2021). This phenomenon, known as the ‘self-fulfilling prophecy’, is well documented: in intracerebral haemorrhage, early withdrawal of life support distorts predictive models and amplifies poor prognoses (Becker 2001, Hemphill 2010, Brizzi 2012, Graham 2020). A meta-analysis by the European Resuscitation Council and the European Society of Anaesthesiology and Intensive Care emphasises that only a small number of studies adjust their assessment for self-fulfilling prophecy bias, as decisions to limit care are often made before prognostic certainty is established (Sandroni 2014). Recent recommendations therefore emphasise the need for a multimodal approach, postponing the final decision for at least 72 hours or more, and combining several tools (clinical scales, biomarkers, EEG, evoked potentials, advanced imaging) in order to reduce the likelihood of hasty and unfairly pessimistic decisions (Hwang 2024).

C. Living with a disability

Although a neurological disability seems unbearable to many people, studies have shown that it is possible to get used to a disability and that, despite their disability, patients are happy that they have continued to receive treatment (Jüttler 2011, Bruno 2011).

D. The diagnosis of cognitive impairment as a determining factor

The identification of dementia, mild cognitive impairment or neuropsychological sequelae following brain injury can significantly influence the decision not to resuscitate. Indeed, the presence of cognitive deficits is often perceived by caregivers as a marker of increased vulnerability and poor functional prognosis, sometimes leading to a limitation of care (Luth 2021). However, the relationship between cognitive impairment and quality of life is far from linear. Several studies show that many patients with moderate dementia or mild cognitive impairment maintain a satisfactory level of subjective well-being and a meaningful existence, particularly thanks to good social support and environmental adaptations (Logsdon 2002; Clare 2019). Furthermore, neuropsychological sequelae, such as trouble with concentration, memory or judgement, do not systematically translate into an inability to experience pleasure, interact socially or participate in personal projects (Gitlin 2020). The major risk is that a diagnosis of cognitive impairment will become an implicit criterion for futility of treatment, leading to decisions not to resuscitate based on preconceptions rather than on an individualised assessment of the patient's quality of life and preferences. This issue highlights the importance of a nuanced and ethical approach, where medical decisions must take into account not only cognitive status, but also the patient's life experience and personal values (Chong 2021).

E. The difficulty of establishing whether a patient has capacity.

Assessing a patient's capacity at the time of admission is a crucial but often complex step in the medical decision-making process, particularly for decisions regarding resuscitation status. Several studies highlight that this assessment is frequently underestimated or performed in a non-systematic manner, which can lead to decisions being made without true informed consent (Young, 2018, Dunn 2020). Decision-making capacity, defined as the ability to understand and evaluate medical information and make decisions consistent with one's values, can be temporarily impaired by illness, pain, medication or the stress of hospitalization. Furthermore, the use of standardised cognitive and decision-making assessment tools, remains insufficiently widespread in hospital departments, despite their proven usefulness in objectively assessing the patient’s capacity and guiding clinicians. This shortcoming exposes patients to an increased risk of inappropriate advance decisions, particularly with regard to ceiling of treatment (Silveira et al., 2021). Improving caregiver training in assessing decision-making capacity and systematising its screening are therefore essential steps in ensuring effective respect for patient autonomy.

In reality, we see that neurologists and neuropsychologists are often consulted when the patient wants to be ‘resuscitated’ even though caregivers are doubtful about their prognosis (e.g. due to advanced age). They question whether this decision is ‘reasonable’. Conversely, a neurological consultation is rarely requested if the patient states that they do not want to be resuscitated and if this decision is in line with the assessment of the medical and nursing team.

III. Implicit and explicit stigmatisation: mechanisms and effects

A. DNAR status as a marker of stigma

Entering ‘Not for resuscitation’ in a medical record is not simply a matter of not attempting cardiopulmonary resuscitation (CPR). Several studies show that this decision has an overall influence on patient care, often resulting in fewer diagnostic tests, limited therapeutic interventions and earlier referral to palliative care (Dingham 2021). This dynamic has been described as a ‘disengagement spiral’: the initial decision not to resuscitate becomes a trigger for a gradual reduction in the intensity of care, leading to an insidious reduction in the patient's medical priority. This phenomenon poses a major ethical risk, particularly when the decision to limit treatment is taken prematurely or without thorough consultation, as it can compromise the quality and continuity of care, regardless of the patient's actual wishes. Recognition of this spiral therefore requires increased vigilance and the establishment of protocols to ensure that the decision not to resuscitate does not automatically lead to an unjustified reduction in other care (De Georgia 2022).

In most hospitals in Switzerland, care is still categorized; the patient may be admitted to intensive care in the event of deterioration, the patient may only receive maximum treatment on the ward or the patient is for ‘comfort care’ *(which generally means they are no longer for active treatment – translator’s note).*

B. Projection of the caregiver's anxieties

When faced with a serious neurological condition, caregivers may experience deep anxiety that consciously or unconsciously influences their position on resuscitation. The progression of conditions such as massive strokes, anoxic encephalopathies or neurodegenerative diseases is often unpredictable, plunging teams into a state of prognostic uncertainty that is difficult to cope with (Silvennoinen et al., 2014). This uncertainty is compounded by the fear of returning to a ‘life without consciousness’, locked in syndrome or a state of extreme dependence that is considered incompatible with a dignified quality of life (Holloway 2013). In this context, resuscitation may appear not as an act of salvation, but as the risk of condemning the patient to an unbearable existence. These projections are often exacerbated by previous experiences perceived as dehumanising or by a lack of specialist training (Amacher, 2024) in neurological palliative care, increasing the risk that the decision will be based more on the caregiver's emotions than on a rigorous and collaborative assessment. Thus, the symbolic burden and unpredictability of neurological diseases sometimes act as a distorting lens, leading to resuscitation being initiated or refused too early or too late, to the detriment of the patient's real interests (Sasposnik, 2016).

C. Fear of loss of autonomy

In Switzerland, individual autonomy and independence are deeply rooted pillars of political and social culture. The right to refuse treatment or resuscitation, as expressed through advance directives or DNAR status, reflects a collective value of control over one's medical destiny. Surveys show that more than 80% of Swiss adults support the legality of assisted suicide, reflecting a climate of trust in institutions and a value placed on self-determination at the end of life (Vilpert 2020 a) and b). Furthermore, a study on medical decisions at the end of life reveals that, despite some nuances, Swiss language regions show a generally stronger tendency to discuss choices with patients in German-speaking regions compared to the Italian or French-speaking regions (Hurst et al., 2018). Finally, while maintaining autonomy is central, Swiss society also attaches importance to economic independence and individual control, even in old age: a survey shows that 91% of Swiss people consider this ability to act freely and be connected to their community to be essential, an ideal that is integral to their well-being (Swiss Life Group, 2024).

D. Does membership of EXIT have an influence on resuscitation status?

Membership of an organisation such as EXIT, which campaigns for the right to assisted suicide, seems to influence the likelihood of a patient adopting a do-not-resuscitate status (DNAR). Several Swiss studies show that members of such associations are significantly more likely to have written advance directives, to be in favour of having ceilings of care, and to express an explicit desire to avoid prolonged treatments perceived as disproportionate. This inclination to anticipate the end of life is based on a strong value placed on autonomy, the rejection of dependence, and the desire for control over the circumstances of death. Membership of EXIT does not automatically presuppose recourse to assisted suicide but reflects an ethical and existential stance in which resuscitation may be perceived as an unacceptable intrusion if it prolongs a state of suffering or indignity. In this context, DNAR status becomes a coherent expression of this vision of dignity, self-respect and individual freedom (Blanc, 2025).

E. Do the costs of institutionalisation play a role in DNAR?

The cost of institutionalisation appears to play an indirect but real role in decisions regarding do-not-resuscitate (DNAR) status. In Switzerland, as in other Western countries, the costs associated with care in a nursing home are high and often shared between insurance companies, patients and their families. This economic reality sometimes influences the preferences of elderly patients, who fear becoming a financial burden on their loved ones. A Swiss study conducted by Vilpert (2020) found that fear of dependence and loss of dignity is frequently linked to economic concerns. From the viewpoint of the caregiver, ethical studies indicate that the patient's socio-economic context – isolation, frailty, anticipated cost of care – can unconsciously influence the inclination to suggest DNAR or not (Bernat 2005). This phenomenon, although rarely explicitly stated, can lead to a shift towards biased decision-making, particularly in elderly or chronically dependent patients. Hence the importance of maintaining shared clinical and ethical criteria as the sole basis for decisions on treatment limitation, regardless of the patient's economic status.

F. What influence do next of kin have on DNAR?

Next of kin often play a decisive role in the decision not to resuscitate (DNAR), especially when the patient is cognitively vulnerable or has lost their independence. In practice, relatives often act as mediators between the patient and the healthcare team, sometimes even as spokespersons when the patient's judgement is impaired. Their interpretation of the patient's wishes, influenced by their own relationship with dependency, suffering or death, can have a strong influence on medical decisions (Hickman et al., 2011). In certain situations, particularly in neurology, the family caregiver becomes a de facto central figure in the decision-making process, which can be a source of ethical tensions if their interests or emotions take precedence over those of the patient. Several studies have shown that caregivers can be influenced, sometimes unconsciously, by the level of involvement, emotional distress or pressure of the family caregiver, leading to advance decisions to limit treatment (Holloway et al., 2016). In Switzerland, where individual autonomy is highly valued, advance directives are supposed to guide this process, but in their absence or if they are ambiguous, the next of kin's opinion becomes a decisive factor, highlighting the need to better integrate them into shared decision-making mechanisms and support them in their role. Thus, the next of kin is at once a resource, a link, and sometimes an influencing factor in DNAR decisions, justifying enhanced attention to the ethics of the situation and how we communicate with them.

IV. Ways to avoid stigmatisation

A. Promoting a nuanced medical culture of disability

It is essential to train healthcare professionals in the diversity of neurological trajectories and the philosophy of disability. Understanding that life with a disability is not necessarily a life without quality is a prerequisite for any ethical assessment.

B. Value the patient's subjective experience

Where possible, the patient's wishes should guide care. In their absence, relatives should be consulted with discernment, based on the patient's presumed wishes.

C. Make the DNAR status dynamic and subject to review

Abandon the fixed nature of the DNAR status and make it a thoughtful, evolving and documented process.

D. Avoid self-fulfilling prophecies

Wait a reasonable amount of time before making decisions about not resuscitating in the acute phase, especially for severe brain injuries.

E. Take into account the emotional life of the caregiver

Allow space for ethical and psychological reflection to help doctors identify personal factors that are influencing their decisions.

F. Include the neurologist in the discussion of resuscitation status

The discussion on resuscitation status should not be made by the most junior F1 but by the person with the greatest knowledge of the likely prognosis.

Conclusion

The resuscitation status of patients with neurological disorders must under no circumstances become a shortcut to therapeutic abandonment. It must be the result of an ethical, collegiate, rigorous and emotionally clear-headed approach. Stigmatisation is a real risk, which makes open and frank dialogue with both the patient and the healthcare team essential.

In-depth knowledge of neurological conditions and their relative prognoses is essential for informed decision-making.

Furthermore, collective reflection on the place accorded to autonomy—and its limits—in our society merits further attention.

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*Conference **4 - Groupworks***

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Clinical vignettes – Workshop on resuscitation status

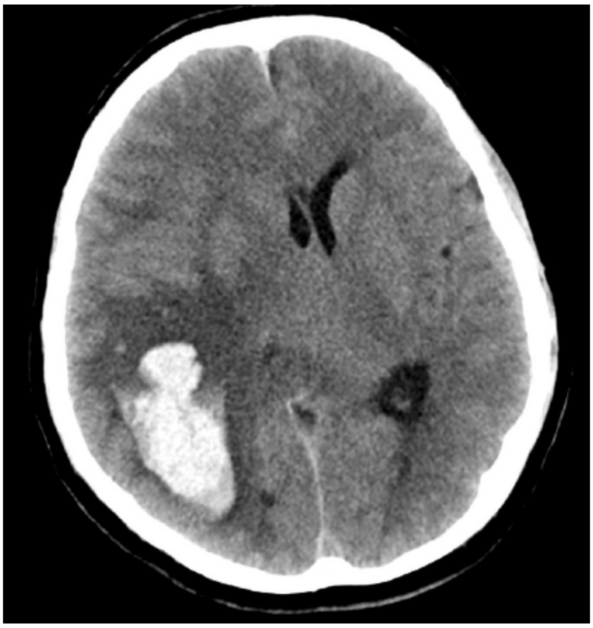
(The images are generic images for illustrative purposes only.)

1) This is an 80-year-old female patient, a former factory worker, now retired, who until now was in very good health and not taking any medication.
For about a year, she has been experiencing mild cognitive impairment, mainly memory problems according to her daughter, requiring some support with managing her finances. No diagnostic tests have yet been performed. However, the patient remains independent at home.
She is a widow and lives alone. Her daughter, her only relative, lives an hour's drive away and works full-time. She found her mother at home, 24 hours after the last known contact, in a confused state with a left hemiparesis.

A brain CT scan with angiography revealed a right parietal lobe haematoma, associated with probable cerebral amyloid angiopathy — a diagnosis that also retrospectively explains the previous cognitive impairment.
The patient had never written an advance directive or explicitly discussed her wishes in the event of a critical illness. She had simply mentioned on several occasions, without giving details, that she did not want 'life-sustaining treatment'.

- **Question for the workshop:**

  What approach would you take to determine the resuscitation status in this situation?

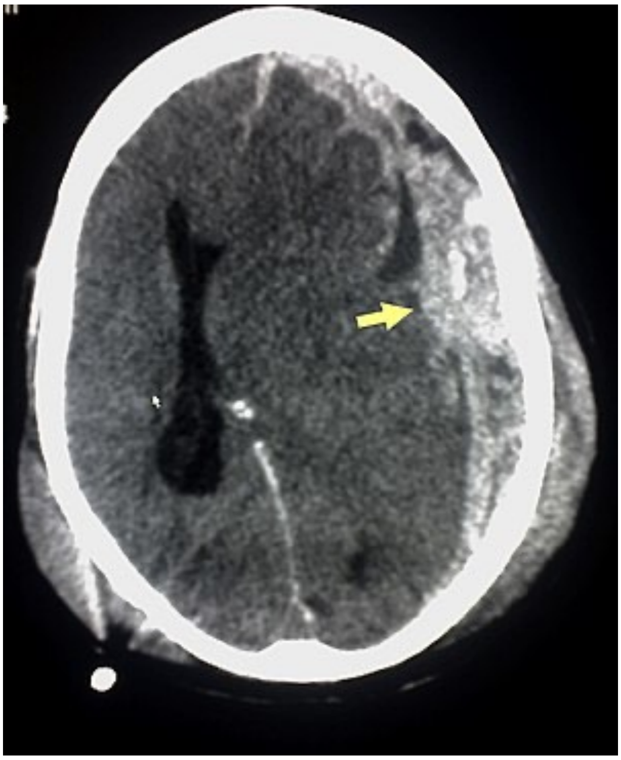


2) An 18-year-old male patient, an apprentice mechanic, was involved in a road traffic accident that resulted in severe traumatic brain injury with subdural haematoma and signs of herniation. He is urgently transferred to the university hospital, where cranial decompression is performed.
After several days, he is extubated and breathing spontaneously. However, no meaningful contact is possible: the patient remains unresponsive and is fed via a nasogastric tube. He has a right motor hemiparesis, possibly associated with aphasia.
Before the accident, during a visit to a nursing home to see his grandmother who had Alzheimer's disease, the patient reportedly told his sisters that he would never want to live in a state of extreme dependence, saying that he would rather 'die than be a vegetable'. No advance directive had been drawn up.
Six weeks after these events, with no significant change in his neurological condition, the patient is transferred to your department in his home canton. You must now reassess his **resuscitation status**, as well as the question of whether to perform a **percutaneous endoscopic gastrostomy (PEG)**.
The family situation is complex: his parents are divorced. The father expresses the wish that 'everything be done', while his mother, focussing on comments made by his sisters, questions the merits of intensive care.

- **Question for the workshop:**

  What approach do you take to determine the resuscitation status in this situation?

  And how would you approach the decision whether or not to insert a PEG tube?



3) This is an 85-year-old man, a professor of French literature, who is still very active intellectually. He is currently working on a book about the writings of Jean-Jacques Rousseau.

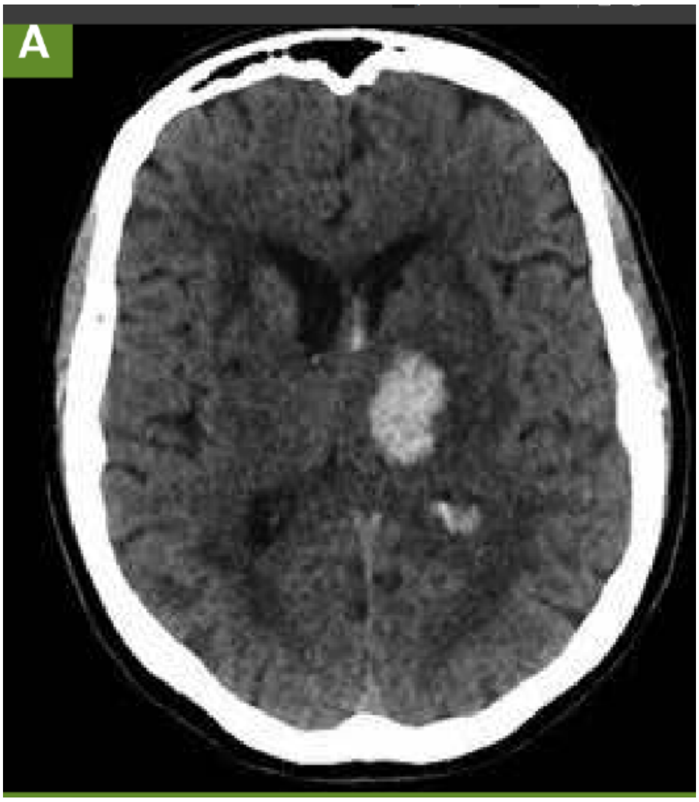
His medical history includes high blood pressure and type 2 diabetes. He is admitted to hospital following a cerebral haemorrhage affecting the internal capsule, causing right-sided hemiparesis. During the interview with the medical team, the patient clearly and firmly expresses his wish to **do everything possible** to preserve his health, insisting that he 'absolutely wants to finish his book.' When asked about resuscitation, he replies without hesitation: 'Of course, medicine has made a lot of progress!'

However, some members of the healthcare team are critical of this position, believing it to be unrealistic given the functional prognosis and the patient's age.

- **Question for the workshop:**

  How would you handle this situation?

  How would you reconcile the patient's autonomy with the healthcare team's concerns?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