HAUTE AUTORITÉ DE SANTÉ

CARE PATHWAY GUIDE

How to implement continuous deep sedation until death?

Les Parcours de Soins

February 2018

This guide, its quick reference guide and the bibliographic report can be downloaded at:
www.has-sante.fr

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List of abbreviations

MA	Marketing authorisation
ANSM	*Agence nationale de sécurité du médicament et des produits de santé* [French National Agency for Medicines and Health Products Safety]
ARS	*Agence régionale de santé* [regional health agency]
CMQ	*Collège des médecins du Québec* [professional order of Quebec physicians]
ECPA	*Évaluation comportementale de la douleur chez la personne âgée* [Behavioural assessment of pain in the elderly]
EMSP	*Équipe mobile de soins palliatifs* [community palliative care team, hospital palliative care support team]
EHPAD	*Établissement d'hébergement pour personnes âgées dépendantes* [Residential care institution for dependent adults]
ERRSPP	*Équipe ressource régionale de soins palliatifs pédiatriques* [Regional paediatric palliative care support team]
HAD	*Hospitalisation à domicile* [Hospitalisation at home]
HAS	*Haute autorité de santé* [French National Authority for Health]
IV	Intravenous
RASS	Richmond Agitation-Sedation Scale
BPG	Best practice guideline
SPC	Summary of Product Characteristics
RDOS	Respiratory Distress Observation Scale
SAMU	*Service d'aide médicale urgente* [Emergency medical aid service]
SC	Subcutaneous
SFAP	*Société française d'accompagnement et de soins palliatifs* [French Society for Supportive and Palliative Care]
SPASAD	*Service polyvalent d'aide et de soins à domicile* [Multidisciplinary home aid and care service]
CDSUD	Continuous deep sedation until death
SSIAD	*Service de soins infirmiers à domicile* [Home nursing care service]
PCU	Palliative care unit
WTHD	Wish to hasten death

Introduction

Continuous deep sedation until death (CDSUD) of a patient is a procedure covered by the French Law of 2 February 2016 *creating new rights for patients and the terminally ill*, which follows the French Law of 22 April 2005 *on the rights of patients and the terminally ill* and by the Decree of 3 August 2016 *amending the code of medical ethics, and on collegial procedures and the use of continuous deep sedation until death.*

To help professionals manage their patients at end of life, this guide describes how to implement CDSUD in the situations indicated by French law:

- at the request of the patient, to avoid any suffering and unreasonable obstinacy: it is considered when there is no other solution to appease the suffering of the patient at end of life;
- in a patient who cannot express his/her wishes, in case of stopping of life-sustaining treatments.

CDSUD causes altered consciousness which continues until death. This guide specifies the conditions for performing CDSUD at home, at a residential care institution for dependent adults (EHPAD) or at a healthcare organisation.

This document does not cover the decision-making process for stopping treatments, emergency palliative sedations, transient or potentially reversible sedations and sedations for certain groups of patients undergoing highly specialised care (neonatology). For paediatrics, it concerns only children who have the maturity and capacity for judgement to “ask” to avoid suffering or to stop treatment; it does not deal with sedative practices at medico-educational organisations and other non-hospital healthcare organisations.

This guide is supplementary to the works of the French Society for Supportive and Palliative Care (SFAP), which has created point of reference sheet to guide best practices in sedation.

This document is directed toward all healthcare professionals, in particular primary care professionals. Even though CDSUD at the patient’s request is currently a very uncommon procedure at home, the primary care physician should be able to take this action, even if he/she feels isolated in his/her territory.

This guide offers tools to help in decision making and implementation of continuous deep sedation until death.

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1. Definitions of palliative sedation practices

"Palliative sedation seeks, through use of medicines, to reduce alertness, which can lead to loss of awareness. Its goal is to reduce or eliminate the perception of a situation seen as intolerable by the patient, when all the other means available and suitable for the situation have been proposed and/or implemented, without providing the expected relief.

The sedation can be intermittent, transient or continuous[1]."

Sedation is implemented during palliative care[2] of a patient in an advanced or terminal phase, in an emergency (massive haemorrhage, asphyxia, respiratory distress, etc.) or to respond to the patient's refractory suffering.

Palliative sedation practices at end of life include[3]:

- sedation called "proportionate" to the severity of the symptoms, which can allow the patient to maintain a relational life; it may be transient, intermittent and potentially reversible. The physician should propose it to the advanced or terminal patient to respond to refractory suffering;
- continuous deep sedation: suspension of consciousness until death; this type of sedation is the subject of this document.

They should be implemented in the context of the French Law of 2 February 2016, described in Appendix 1 (Articles L. 1110-5-3 and L. 1110-5-2).

They are different from anxiolytic practices, which do not cause any significant change in alertness (Richmond score ≥ -1)[4].

The indications and conditions are described in the guidelines[5] coordinated by the French Society for Supportive and Palliative Care (SFAP).

Distinguishing continuous deep sedation from euthanasia

Six characteristics differentiate continuous deep sedation until death from euthanasia: **intent, method to achieve the result, procedure, result, temporality and legislation.**

[1] http://www.sfap.org/system/files/sedation-phase-terminale.pdf

[2] *The palliative period is the period of care during which the objectives of care and treatments are focused on quality of life and, when possible, duration of life, despite the impossibility of a cure.*

[3] *SEDAPALL typology describes palliative sedation practices at end of life according to three axes: duration, depth and consent (http://www.sfap.org/system/files/sedapall_vf1_0.pdf).*

[4] *Curtis N. Sessler, Mark S. Gosnell, Mary Jo Grap, Gretchen M. Brophy, Pam V. O'Neal, Kimberly A. Keane, Eljim P. Tesoro, and R. K. Elswick. The Richmond Agitation–Sedation Scale, Validity and Reliability in Adult Intensive Care Unit Patients. Am J Respir Crit Care Med Vol 166. pp 1338–1344, 2002 (https://www.atsjournals.org/doi/full/10.1164/rccm.2107138#readcube-epdf)*

[5] http://www.sfap.org/rubrique/les-recommandations-sur-la-sedation

Table 1. Differences between continuous deep sedation until death and euthanasia

	Continuous deep sedation until death	Euthanasia
Intent	Relieve refractory suffering	Respond to the patient's request for death
Method	Deeply alter consciousness	Cause death
Procedure	Use of a sedative with suitable doses to obtain deep sedation	Use of a medicinal product at a lethal dose
Result	Continuous deep sedation until death due to the natural course of the disease	Immediate death of the patient
Temporality	Death occurs within a time frame that cannot be predicted	Death is caused quickly by a lethal product
Legislation	Authorised by French law	Illegal (homicide, poisoning, etc.)

As a result, continuous deep sedation until death is not a response to a request for euthanasia: it is a response to the refractory suffering of the patient, who should be informed of this therapeutic option.

2. When can continuous deep sedation until death be indicated?

The French Law of 2 February 2016 *creating new rights for patients and the terminally ill* (Appendix 1) regulates the circumstances in which continuous deep sedation until death (CDSUD) is implemented.

- **A patient can request** CDSUD in the following two circumstances:
  - if a patient has suffering refractory to treatments, when he/she has a serious and incurable condition which is life-threatening in the short term;
  - if a patient with a serious and incurable condition decides to stop treatment, and this decision has life-threatening consequences in the short term and is likely to result in unbearable suffering.
- In a **patient who cannot express his/her wishes**: if the physician stops life-sustaining treatment to avoid unreasonable obstinacy, the physician implements CDSUD unless the patient has objected to this in his/her advance directive.

A minor, if he/she has a capacity for judgement deemed sufficient, may request implementation of CDSUD. Consent of the parties holding parental authority is required (see § 3.2.4).

An adult under legal guardianship[6] makes decisions about him/herself. If he/she cannot make an informed decision, the guardian helps or represents the patient according to his/her health status. The guardian cannot request CDSUD without the authorisation of the judge or family council, but his/her consent is required[7] to implement it.

[6] *Article 459 of the Civil Code:*
https://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006070721&idArticle=LEGIARTI000006427734&dateTexte=&categorieLien=cid

[7] *Article R. 4127-42 of the Public Health Code:*
https://www.legifrance.gouv.fr/affichCodeArticle.do?cidTexte=LEGITEXT000006072665&idArticle=LEGIARTI000006912905

3. What to do before implementing continuous deep sedation in a patient with a serious and incurable condition

Each situation is **unique** and complex: it requires a careful and in-depth assessment. The following steps are imposed on the physician to respect both the wishes of the patient and the French law:

- listening to, understanding and analysing the patient's request;
- verifying, through a collegial procedure[8], that the conditions established by French law are met, that the patient has the necessary capacity for judgement and that his/her request is made freely after he/she is provided with fair, clear and appropriate information.

3.1 Listening to, understanding and analysing the patient's request

The patient may express his/her wish to avoid any suffering to the physician who treats him/her for his/her serious condition, but also to any person he/she has contact with (substitute decision maker, family and friends, any healthcare professional, psychologist, home aide, volunteers, etc.).

Therefore, the sharing of information among professionals and with those close to the patient (with the patient's agreement) is essential, as is the traceability of interviews in the medical file.

The dynamic and changing nature of the request will be taken into account during **repeated interviews** in a **time frame appropriate to the unique situation** of the patient, taking care **not to delay** implementation of means to **relieve the patient**.

Therefore, the assessment of the patient and his/her request should be carried out by the multiprofessional team in charge of the patient's care. Depending on his/her experience in end-of-life care, the physician **will be able to early rely on a skilled palliative care team,** during an interview in its presence, by phone or video conferencing (remote expertise). The list and directory of these professionals are described in Focus 1.

Analysis of the request focuses on:

- the patient's knowledge of his/her disease, its course and his/her prognosis;
- the social, family, cultural and spiritual (existential and religious) context;
- the patient's life history, his/her values, sense of life, illness and death;
- the psychological context (psychological suffering, anxiety, etc.), including any possible psychiatric disorder (depression, etc.);
- the patient's knowledge, expectations, fears, thoughts and uncertainties regarding the proposed treatments and the conditions of his/her death;
- the reasons for the request, other than to relieve suffering: request or hope to accelerate death or to control it, alternative to euthanasia or assisted suicide, fear of suffering, etc.

Because a request for CDSUD or stopping life-sustaining treatments reflects suffering that is usually global, an assessment by a psychiatrist or clinical psychologist is highly recommended, with the patient's consent and within an appropriate time frame. This helps to assess the psychological condition (demoralisation, etc.) or psychiatric condition (depression, anxiety, etc.) of the patient (means of access in Focus 1).

[8] *Collegial procedure is a process before decision-making : discussion about withdrawal / withholding of disease-modifying or life-sustaining treatment (or device), during a multi-disciplinary team meeting described in 3.2.1 paragraph and focus 2*

A request from a minor patient at end of life will be listened to in the same manner as the request of an adult. This exceptional situation requires:

- a three-sided approach of reflection and dialogue between the minor, the parents and the professionals (care team of the minor, paediatrician, child psychiatrist, psychologist, etc.);
- support that should be global, of the child, his/her friends and family and the care team.

In addition to the elements of analysis described for the adult:

- the maturity of the minor, his/her level of understanding of the clinical situation, his/her capacity for judgement and his/her degree of autonomy in his/her request should be evaluated jointly by a team: professional(s) whom the child trusts and, if applicable, the assistance of a child psychiatrist or a clinical psychologist;
- the parents will be asked for their perception of their child's suffering;
- communication between the parents and the minor is of particular importance in this context and should be facilitated, if necessary, by the presence of a third-party professional. The parents' support is essential.

The patient (adult or minor) is informed of the therapeutic options, including other sedation practices (proportionate, reversible, etc.) and the terms of the French law. The information should be fair, clear and appropriate.

His/her requests and those of the family are recorded in the medical file.

3.2 Verifying that the conditions established by French law are met

3.2.1 Description of the collegial procedure

The collegial procedure is the dialogue between the physician in charge of the patient's care and the members present from the care team (if such a team exists) and the reasoned opinion of at least one physician outside of the team, called on as a consultant. It should consist of a collective deliberation process between individuals with reasoned, and possibly different, opinions.

It is required by law before making a decision for CDSUD (Appendix 1).

► Objectives

To share information about the patient (his person, his/her living context, his/her illness and the treatments performed or proposed, his/her wishes) and exchange points of view in order to:

- make a global assessment of the situation and a medical assessment of the patient's condition, referring to best practice guidelines;
- answer the following questions to verify that the conditions set by French law are met:
    - is the suffering refractory and is the condition life-threatening in the short term?
    - does the stopping of treatment requested by the patient have life-threatening consequences in the short term and is it likely to lead to unbearable suffering?
    - is the use of continuous deep sedation in combination with a decision to stop life-sustaining treatments done in accordance with French law?
- verify that the request is made in a free and informed manner and, if applicable, assess the patient's capacity for judgement.

The collegial procedure:

- assesses the criteria listed above and does not make a value judgement on the patient's request;
- strives to eliminate, by exposing them to others, inappropriate reasons to act: team fatigue, invasive emotion, staff management, lack of means, etc.;
- can open reflection on the dimension of uncertainty and doubt and other areas of the care project.

► Professionals involved in the collegial procedure

The assessment is **interdisciplinary and multiprofessional**: the collegial procedure includes all professionals involved in the patient's care and an outside physician called on as a consultant. Non-medical professionals involved in this care play an important role.

The team that will implement the deep sedation should have participated in the collegial procedure.

Table 2. Professionals participating in the collegial procedure

The professionals who participate in the collegial procedure are the members present from the care team.

<table>
<tr><th>Collegial procedure</th><th>At home</th><th>At EHPAD</th><th>At a healthcare organisation</th></tr>
<tr><td>Organisation/ coordination</td><td>primary care team, general practitioner, physician providing care to the patient, hospital at home coordinating professional, network, community palliative care team, hospital palliative care support team, regional paediatric palliative care support team, home nursing care service, nursing care centre, etc.</td><td>same resources as local, if available
nurse, coordinating physician</td><td>physician in charge of the patient's care or health officer
hospital palliative care support team, regional paediatric palliative care support team, community palliative care team, network</td></tr>
<tr><td rowspan="5">Participants</td><td colspan="3">treating primary care professionals, general practitioner, or physician in charge of the patient's care</td></tr>
<tr><td colspan="3">nurses and caregivers,
clinical psychologist, psychiatrist,
physician from hospital palliative care support team, regional paediatric palliative care support team, community palliative care team</td></tr>
<tr><td>home aide, nurse from SSIAD, SPASAD, etc.</td><td>health officer,
coordinating nurse
coordinating physician</td><td>health officer</td></tr>
<tr><td colspan="2">HAD palliative care physician</td><td>treating physician</td></tr>
<tr><td colspan="3">other professionals, depending on the situation: geriatrician, paediatrician, other requested specialist physician, physiotherapist, advanced practice nurse, psychomotor specialist, social worker, pharmacist and any professional involved in the patient's care</td></tr>
<tr><td rowspan="2">Consulting physician</td><td colspan="2">specialised support through the directory of palliative care facilities (http://www.sfap.org/annuaire)</td><td>physician from another department or the referring PCU
physician from hospital palliative care support team or Regional paediatric palliative care support team or community palliative care team, if available</td></tr>
<tr><td colspan="3">or another colleague with no hierarchical connection, who meets the criteria listed in Focus 2 at EHPAD, calling on the coordinating physician is not recommended[9].</td></tr>
</table>

SSIAD: service de soins infirmiers à domicile [home nursing care service], SPASAD: service polyvalent d'aide et de soins à domicile [multidisciplinary home aid and care service], HAD: hospitalisation à domicile [hospitalisation at home], PCU: palliative care unit

The professionals listed in the table are not always routinely involved in the patient's care. When they are involved, **their presence is recommended**.

Information is shared (unless the patient requests otherwise) and everyone involved is bound by professional secrecy.

[9] *The Conseil national de l'ordre des médecins [National Council of Physicians] recommends not asking the coordinating physician of the institution as a consultant because he/she is part of the care team; the coordinating physician of another institution is possible.*

The substitute decision maker, friends and family and, if applicable, religious representative or volunteer do not participate in the collegial procedure, but will have been consulted beforehand.

► Conditions

The conditions of the collegial procedure and the situations in which they can occur, which can be varied, are described in Focus 2.

3.2.2 FIRST SITUATION: collegial assessment in a conscious patient who requests CDSUD due to refractory suffering

The collegial assessment of the request is **urgent** to be able to alleviate the patient's suffering.

► Is the suffering refractory?

Definition

Suffering is said to be refractory if all available and suitable therapeutic and support means have been proposed and/or implemented:

- without providing the relief expected by the patient;
- or they cause unacceptable adverse effects;
- or their therapeutic effects are not likely to act within a time frame acceptable for the patient.

The patient alone is able to assess the unbearable nature of his/her suffering, of the adverse effects, or of the time of action of the treatment.

Diagnosis

The diagnosis of refractory suffering is based on a shared approach between the physician, the care team and the patient, or a three-sided approach with the parents in the case of a minor (with his/her agreement), because it is necessary to:

- analyse the suffering: usually **global**, the physical aspects (pain, dyspnoea, etc.), mental (anxiety, depression, etc.), social (relationship with friends and family, the care team, abandonment experienced, etc.), and existential (loss of bearings, dignity, self-esteem, etc.) aspects are often interconnected; mental suffering and existential suffering can contribute to making physical suffering unbearable;
- assess its refractory nature: have all means been implemented or proposed to provide relief, including listening, support (social, spiritual, etc.), psychological care, treatments with medicinal products, etc.;
- take into account the fact that the request for CDSUD may be made based on a desire to hasten death, which should be understood as an integral part of suffering. This desire is changing, dynamic and potentially reversible with treatment of physical or mental suffering;
- respect the patient's right to refuse the alternative therapies proposed to him/her.

Assessment: justification is described in the SFAP guide[10]

It is **multidimensional and multiprofessional:**

- **multidimensional**: assessment of global suffering (see above); emotional, cognitive and dynamic pyscho-social condition; subjective assessment by the patient of the situation;
- **multiprofessional**:
  - members of the care team in charge of the patient, of the home medico-social team,

[10] http://www.sfap.org/system/files/refractaire_v5_24052017_0.pdf

- skilled palliative care team (EMSP [*Équipe mobile de soins palliatifs* :community palliative care team, hospital palliative care support team], ERRSPP [*Équipe ressource régionale de soins palliatifs pédiatriques* : regional paediatric palliative care support team], experienced HAD team, network),
- psychiatrist or clinical psychologist (with specific training for end-of-life patients): essential in case of mental suffering, assessment is strongly recommended in all cases because mental suffering is usually interconnected with other types of suffering (physical, social and existential),
- opinion of specialists depending on needs: pain specialist [physician, nurse], anaesthetist, oncologist, clinical pharmacist, etc. to ensure that all therapeutic options have been considered.

The assessments should be repeated after appropriate therapeutic approaches**, if time permits:** persistence of suffering will be identified.
HOWEVER, the implementation of appropriate means to provide relief to the patient should not be delayed.

The content of the assessment is described in **Table 3 of Focus 3**.

In case of isolated, persistent mental and/or existential suffering, a temporary and reversible sedation may be proposed.

► Is the patient's condition life-threatening in the short term?

If death is near, expected **in a few hours or a few days**, CDSUD may be considered.

The justification is described in the SFAP guide[11] and in the bibliographic reference[12]. This time of a few hours to a few days is the time frame took on by the European Association of Palliative Care.

In an emergency or if the time frame is very short (a few hours), it is possible to start with a proportionate sedation. The depth of this sedation will be adapted to the relief of suffering of the patient (Chap.1).

To implement CDSUD, the prognostic assessment should be **multi-professional** because estimating life expectancy is difficult, especially for elderly patients with multiple diseases. Some signs and symptoms may help to assess the prognosis, in addition to the clinical judgement of the physician.

Among other things, it is based on:

- the extent of the disease and its rate of progression;
- the speed of the functional decline;
- the presence of failure of a vital function.

Monitoring of the individual makes it possible to identify changes in signs and symptoms, which may suggest that he/she is entering his/her final days:

- anorexia-cachexia, dysphagia, oedema, dyspnoea;
- oliguria or anuria;
- severe asthenia with somnolence;
- change in vital signs (drop in blood pressure, weak pulse, irregular breathing, desaturation, cold or mottled extremities).

A drop in score on the Palliative Performance Scale going from 40% or 30% to 20% in 3 days is suggestive of death in less than 2 weeks (Appendix 2).

If death is expected in a **time frame exceeding a few days** and symptoms are refractory, **reversible sedation with a level proportionate** to the need for relief is discussed with the patient.

[11] http://www.sfap.org/system/files/courtterme_v2_16052017_0.pdf
[12] www.has-sante.fr *(T.B.A.)*

3.2.3 SECOND SITUATION: collegial assessment in a conscious patient whose decision to stop treatment has life-threatening consequences in the short term and is likely to result in unbearable suffering

► Patients concerned

A physician may be faced with this situation in case of a request to stop life-sustaining treatments: assisted ventilation (e.g. patient depending on cardiopulmonary assistance, patient with amyotrophic lateral sclerosis or other neurodegenerative disease and dependent on ventilatory support, etc.). **Stopping ventilation will be preceded by CDSUD**.

Patients who have a condition in which stopping treatments means that the condition is life-threatening in the longer term or that they do not have unbearable suffering are **not initially** concerned by CDSUD. **Each situation is unique**: **care appropriate for the symptoms and at the request of the patient will be implemented, including possible proportionate sedation.** Continuous deep sedation until death will be discussed in collegial procedure in case of refractory suffering as described in the first situation.

► Assessment

The decision to stop life-sustaining treatment **needs the time to a personal process:** everything should be done to preserve the interest of the patient, because this request can be a dynamic, changing situation. It is necessary to:

- give time, allow the patient the opportunity to change his/her mind;
- reassess, rephrase, especially therapeutic options;
- track the entire process: information given, discussions, decision;
- explain the situation to friends and family, caregivers, while complying with medical confidentiality.

The collegial assessment should answer two questions:

- does the stopping of treatment requested by the patient have life-threatening consequences in the short term, i.e. **a few hours to a few days**?
- is the stopping of treatment likely to lead to **unbearable suffering**?

The patient's decision to stop treatment can only be implemented after **repeated discussions and processes of collective deliberation** between the patient and everyone involved in the care and treatment:

- aspects to analyse and assess are described in **Table 3 of Focus 3**;
- the patient should reiterate his/her decision within a reasonable time and may call on another member of the medical profession;
- in case of stopping life-sustaining treatments, the physician should obtain the patient's consent and, if applicable, the consent of his/her guardian for the CDSUD; the guardian cannot take the patient's place to request stopping of life-sustaining treatments;

in the case of a minor, a discussion with the parents is essential; a child psychiatrist or clinical psychologist can help to better analyse the wishes of the minor with the family.

3.2.4 Other questions to assess during the collegial procedure

In the two situations described above, other questions should be asked or assessed.

► Is the patient making a free and informed request/decision?

The patient should have all information to make a free and informed choice. These discussions should begin in **advance**, when possible.

Discussions with the patient and friends and family will be shared with members of the team to avoid conflicting information and will be tracked in the file. The professionals will be careful to give only the information that the patient and friends and family want to receive.

Information given to the patient may relate to:

- knowledge of his/her disease, its treatment, its course, his/her prognosis;
- consequences of his/her request, deep change in awareness until death, or of stopping treatments;
- expected effects of the sedation (consciousness, communication, etc.), its risks, especially that of awakening;
- possible therapeutic alternatives (objectives, expected effects and in what time frames, limits, adverse effects), including sedation that is proportionate to the severity of symptoms, intermittent, reversible;
- the existence of possible unforeseen events, even if everything is done so that the situation is controlled;
- precise explanation of the French Law of 2 February 2016 (specifying that sedation is not euthanasia and that it does not seem to have any effect on lifespan);
- conditions for administering sedation, associated analgesic treatments and continuation of nursing and comfort care;
- in case of sedation, care and support for the family.

In paediatrics, the minor must be informed in the same way; the presence of a third-party professional may facilitate communication. Parents are regularly informed of their child's condition.

The physician takes the time to explain, repeatedly, and makes sure that the patient and, where applicable, the parents understand. Communication will be adapted to each patient (age, cognitive disorders, cultural or language differences, etc.), taking into account any sensory impairments the patient may have. An interpreter or a third party facilitating communication may be requested with the agreement of the patient.

► Does the patient have the capacity for judgement to make decisions about his/her care?

The opinion of a specialised professional (geriatrician, paediatrician, neurologist, neuropsychologist, psychiatrist or clinical psychologist, etc.) will be requested if needed (especially for decompensated severe psychiatric illness, major cognitive impairment, profound mental disability, etc.).

It is important to find out if the patient can:

- understand and put together the information received (for example, by asking the patient to rephrase);
- assess the situation, evaluate the consequences of his/her request;
- understand the alternative options;
- express his/her choices and explain them.

The severity of physical symptoms or cognitive or psychiatric disorders may alter his/her capacity for judgement. Assessing the capacity for judgement does not deprive the patient of his/her rights, but, for ethical reasons, the patient's requests must be considered with the utmost caution; it is important to seek traceability of the patient's wishes (advance directives, substitute decision maker, friends and family, etc.).

In paediatrics, the team in charge of the patient's care should evaluate the degree of maturity of the minor to determine if he/she is capable of evaluating the consequences of his/her choices and making decisions about his/her care. The opinion of a psychologist or a psychiatrist is necessary.

For protected adults:

- individuals under guardianship give their consent for matters related to their health;
- **if the individual is under guardianship**, the guardianship judgement must be obtained from the guardian: the guardianship judgement usually describes whether or not the patient is able to make decisions for his/her care and treatment.

► Consent of the parties holding parental authority if the person is a minor

If a minor requests sedation or to stop life-sustaining treatments, the physician must obtain consent for implementation of sedation from both of the parties holding parental authority.

In exceptional cases where there is disagreement between the child and the parents, it is essential that the dialogue be continued so that everyone finds meaning in the decision (dialogue over the next hours or days, use of a psychologist, contact with other family members and persons of importance to the child, etc.).

Care must be taken as to the suffering that these approaches can cause in the child and parents.

CONCLUSION OF THE FIRST TWO SITUATIONS

If the patient has a serious and incurable condition and, after the collegial procedure, it is established that if:

- his suffering is refractory and his/her death is near (a few hours to a few days), CDSUD should be implemented in response to his/her request;
- stopping treatments at his/her request has life-threatening consequences (a few days to a few hours) and may lead to unbearable suffering, he/she should receive CDSUD beforehand.

3.2.5 THIRD SITUATION: collegial assessment in case of stopping life-sustaining treatments in a patient who cannot express his/her wishes

If the collegial procedure results in a decision to stop a life-sustaining treatment to avoid unreasonable obstinacy, the physician should consult the advance directives binding upon him/her. If there are no advance directives, he/she consults the substitute decision maker or, failing that, the family or a friend: the objective is to know the wishes of the patient when he/she was still able to express them, in particular his/her wishes in relation to continuous deep sedation.

The objective of continuous deep sedation until death is to prevent possible suffering. If the only life-sustaining treatment is artificial nutrition and hydration, stopping this treatment can lead to a longer duration of CDSUD (of about 7 to 14 days): this duration requires particular support for friends and family and caregivers.

CONCLUSION OF THE THIRD SITUATION

- When, in a patient who cannot express his/her wishes, the decision is made to stop life-sustaining treatments following a collegial procedure in order to avoid unreasonable obstinacy, CDSUD will be implemented, after verifying that the patient was not previously opposed to this. The substitute decision maker or, failing that, the family or a friend is informed of the reasons for use of CDSUD.

CONCLUSION OF THE CHAPTER

- After the collegial procedure, the physician in charge of the patient's care decides whether or not to perform CDSUD and records the reasons in the patient's file, as well as the entire procedure (Focus 2).

3.3 Talking about sedation with the patient and his/her friends and family before implementation is essential

Friends and family include the substitute decision maker, if one has been designated, and others close to the patient.

Professionals should encourage **prior discussions between the patient and his/her friends and family**: encourage the patient to talk about his/her requests or decisions, help him/her explain the reason for his/her choice and support him/her in discussions with them.

Communication with the patient and his/her friends and family requires empathy, relationship and listening skills. Do not underestimate the weight of words. Information provided to friends and family is done with the patient's consent.

In minors, the support of a professional who is used to handling these issues with children may be required; words will be appropriate for the patient's age and clinical condition, paying attention to all of his/her reactions, verbal or otherwise. The parents are informed and given support.

3.3.1 Communication with the patient

Depending on the wishes of the patient, friends and family he/she has chosen may be present during these discussions, which will include the following:

- explaining the conditions for implementation of CDSUD and ensuring that he/she has understood the consequences of his/her choice: deep sleep maintained until death in order to provide relief;
- **inquiring about the desired location** of sedation (any cultural specificities): home, EHPAD, hospital organisation, to assess feasibility and organise a possible transfer;
- planning with the patient the time of the sedation, **in discussion with his/her friends and family if he/she so wishes**, and meeting his/her requests to the extent possible (final visit beforehand or presence of family during initiation of sedation, prior visit or presence of a religious representative, rituals, etc.);
- explaining to the patient the care he/she will receive and the role of professionals involved;
- informing the patient that if, despite regular monitoring and adjustment of the treatment, an awakening occurs, his/her treatment will be re-adjusted to maintain a deep sedation;
- supporting the patient and answering all of his/her questions, including those about the patient's expectations, fears, knowledge and uncertainties regarding the proposed treatments and their risks;
- inquiring as to whether he/she has any particular request before sedation;
- ensuring the patient that his/her friends and family will be supported and asking the patient if he/she wants them to take part in some care if they so request (e.g. mouth care);
- ensuring that the patient has understood the information given.

3.3.2 Communication with family and friends

Information will only be given with the patient's consent to friends and family members that he/she has designated: the professionals will work with the patient to determine the extent of information to give.

The mental distress of friends and family will be identified and assessed (see Chapter 5). Ambivalence is a normal phenomenon (for example, desire for the patient to no longer suffer vs desire to maintain a relationship with the patient).

The objectives are as follows:

- **in all cases**:
  - to give the information necessary to understand the situation,

- to explain the possibilities for support of a person undergoing CDSUD, i.e. with whom there is no longer any interaction: participation in "taking care": presence, talking to or touching the patient, continuing to talk in his/her presence, etc.,
- to ensure comprehension of the information received by at least one person out of those close to the patient, especially the consequences of sedation until death;

- **if the sedation will be done at the request of the patient**:
  - if friends and family are not present during the interviews with the patient: to explain the patient's right to request CDSUD, the purposes and conditions of the sedation (treatment and their effects), the associated medicines and their risks, discussion about hydration (objectives, benefits and risks) and nutrition, care the patient will receive, support they can receive,
  - to verify that the patient's choice concerning the place of sedation is accepted and feasible (whether home or EHPAD),
  - at home or at EHPAD, explain the options if the situation becomes unmanageable (HAD or transfer to a hospital);
- **in the case of a patient who is unable to express his/her wishes and stopping of life-sustaining treatments**:
  - to explain the objective of the sedation and describe the likely course of the patient's condition, especially in case of only stopping artificial nutrition and hydration,
  - to take into account their opinion for implementation of CDSUD (last family meeting to be organised beforehand or not, etc.),
  - in case of disagreement between friends and family and the care team, the care team may call on a mediator to the extent possible: at a hospital, the mediator is appointed by the institution[13], but hospitalization of the patient may be required for primary care professionals to have access to a mediator;
- **for a minor**, ensure that the parents have the same information, take into account any disagreements between parents and inquire about specific requests (waiting until a close birthday has passed, etc.).

The content of these discussions will be recorded in the file.

4. Implementation of continuous deep sedation

CDSUD requires organisation of practical arrangements, followed by a strict procedure and assessment.

4.1 Role of the professionals involved

4.1.1 Before starting the sedation, ensure that organisational requirements are met

► At home and at EHPAD:

- the team caring for the patient is based on the facilities available: community palliative care team, EMSP, HAD with a team trained in palliative care. If this is not available, the team **contacts a team specialised in palliative care** to have a **contact physician, skilled in palliative care, alerted and reachable** for pharmacological advice (see Focus 1). Telemedicine may facilitate exchanges with this contact physician;

[13] https://www.legifrance.gouv.fr/eli/decret/2005/3/2/SANH0520635D/jo/texte

- a physician (physician in charge of the patient's care, on-call palliative care physician, etc.) and a nurse should be reachable 24 hours a day, and the nurse should be available to travel;

➔ **If this is not possible or if a night nurse is unavailable at EHPAD, HAD is necessary**.

- the team in charge of the patient's care, including, if applicable, the community palliative care team, EMSP, or HAD:
  - ensures for the home that a continuous relay of those around the patient able to make alerts (relatives, volunteers, home aide, etc.) is possible; these caregivers must have been informed and educated about what to do in case of an unexpected event and "who to call when?". Caregiver support for patients receiving palliative home care is described in the key points guide available on the HAS website (https://www.has-sante.fr/portail/upload/docs/application/pdf/2016-07/fpc_sp_a_domicile__web.pdf),
  - provides a fallback bed at a healthcare organisation in case of failure or inability to continue sedation;

➔ **Hospitalisation may be necessary if these conditions are not met.**

  - prepares the "Urgence Pallia" [palliative care emergency] form or any other transfer document to help the physician intervening in an emergency situation (on-duty general practitioner, Centre 15 call centre or continuing care physician, SAMU physician) who will be called in case of an unexpected event (available on: http://www.sfap.org/rubrique/fiche-urgence-pallia-samu-pallia).

► **At healthcare organisations:**

- in departments with little or no experience in sedation and if there is no EMSP, the team in charge of the patient's care **contacts a team specialised in palliative care** to have a **contact physician, skilled in palliative care, alerted and reachable** (see Focus 1);
- if the patient requests a transfer to home, the organisational requirements described above will be verified.

► **In paediatrics:**

- at the hospital, the presence of the child's referring physician is necessary for induction;
- at home, the presence of a palliative care physician is necessary, either from the ERRSPP or a local EMSP that works with the ERRSPP.

At hospitals, especially in paediatrics, and at EHPAD, friends and family should have the opportunity to be present if they and the patient so wish.

4.1.2 Starting and monitoring the sedation

The physician in charge of the patient's care, **responsible for the decision, writes the prescription**: he/she takes advice, if applicable, from the network physician, the EMSP, the ERRSPP or the contact palliative care team.

The nurse will start the administration of medicines **in the presence of the physician** who has decided on and prescribed the sedation, according to the predetermined protocol, especially in case of titration

The nurse and the physician or nursing and medical team monitor the patient until he/she is stabilised (score -4 to -5 on the Richmond scale[14], or 5 on the Rudkin scale, see Focus 4) (Appendix 3), which may require 1 to several hours; then, a close collaboration between physician(s) and nurse(s) is necessary:

- assessment by the nurse: at least twice a day at home, at least 3 times a day at EHPAD and at a hospital;
- daily assessment by the physician.

[14] *Curtis N. Sessler, Mark S. Gosnell, Mary Jo Grap, Gretchen M. Brophy, Pam V. O'Neal, Kimberly A. Keane, Eljim P. Tesoro, and R. K. Elswick. The Richmond Agitation–Sedation Scale, Validity and Reliability in Adult Intensive Care Unit Patients. Am J Respir Crit Care Med Vol 166. pp 1338–1344, 2002 (https://www.atsjournals.org/doi/full/10.1164/rccm.2107138#readcube-epdf*

4.2 Therapeutic implementation and monitoring

Written instructions should be left: protocol for administration and monitoring of treatment, what to do in case of an unexpected event, emergency, **especially at home and at EHPAD.**

4.2.1 Sedation medicines

Since no substance has Marketing Authorisation in this "sedation" indication, this information will be consolidated by a best practice guideline (BPG) written by the HAS and the ANSM[15].

The sedation medicines are described in the SFAP guide[16].

- The most commonly used medicine is midazolam:
  - a first-line medicine, it can be used regardless of age and place, at the hospital, at home or at EHPAD;
  - however, it has several drawbacks: difficult-to-predict maintenance dose, tolerance during long-term use requires dose increases, untimely awakenings due to effect fluctuations, possible resistance;
  - at home or at EHPAD, it is delivered (after hospital medical prescribing) by a hospital pharmacy[17]: the physician who is in charge of the patient's care prescribes midazolam, specifying: "in the context of palliative care"; the medicine must be stored in a secure place;
  - the method of administration is described in Focus 4.
- Long half-life benzodiazepines may be considered: diazepam, clorazepate dipotassium and clonazepam are available in France.
- Sedative neuroleptics (chlorpromazine, levomepromazine) may be used in addition to the benzodiazepine when the sedation is insufficient, in case of confusion or agitation, or if they were initiated before the sedation; their dosages have not been established in CDSUD.
- At the hospital, other medicines are used in second-line by a team that are experts in their use:
  - phenobarbital: possible alternative if midazolam is ineffective, but its dosage and method of administration have not been studied in CDSUD;
  - propofol, sodium oxybate: the skills of an anaesthetist and resuscitation specialist are required.
- **Opioids alone should not be used to induce sedation; they will be continued or increased to control pain and dyspnoea**.

4.2.2 Assessment and monitoring at home, at EHPAD and at healthcare organisation

Aspects of this monitoring will be recorded in a predetermined document: communication log at home and at EHPAD, written and oral communication provided at each shift change of the team at the hospital (example in Appendix 4).

Assessment of the depth of the sedation is done every 15 minutes during the first hour.

Then the patient is monitored at least: twice a day at home, at least 3 times a day at EHPAD and at a hospital.

[15] *This guide may be updated based on the content of the BPG.*

[16] *http://www.sfap.org/system/files/fiche_repere_sfap_miseenoeuvre18mai2017_0.pdf*

[17] *Decree No. 2004-546 of 15 June 2004 on the categories of prescription-only medicinal products and the sale of medicinal products to the public by certain healthcare organisations and amending the Public Health Code and the Social Security Code*

Decision of 20 December 2004 on the sale to the public of certain pharmaceutical products and dietary foods for special medical purposes pharmacies for internal use of healthcare organisations and their reimbursement by national health insurance https://www.legifrance.gouv.fr/eli/decision/2004/12/20/SANH0424327S/jo

In addition to the clinical assessment of the care team, the three criteria that will lead to a dose adjustment or addition or change of product are:

- **depth of the sedation**: score of -4 to -5 on the Richmond Agitation-Sedation Scale or Rudkin score of 5 (patient who cannot be awoken) (Appendix 3); addition of a neuroleptic is anticipated;
- **degree of relief** of the patient: relief from refractory symptoms using hetero-assessment scales, in the absence of stimulation and during care [pain: Algoplus, behavioural assessment of pain in the elderly (ECPA)[18], etc., dyspnoea: Respiratory Distress Observation Scale[19] (RDOS)];
- **adverse effects**: awakening with confusional syndrome, tachyphylaxis with need to increase doses, respiratory depression, vomiting, etc.

Monitoring of physiological parameters (blood pressure, oxygen saturation) is stopped other than monitoring of respiratory rhythm and pulse.

4.2.3 Adjunct treatments

Each medicine administered prior to sedation is assessed: **only treatments that help to maintain the patient's comfort are continued.**

► Analgesics

Analgesic treatments are mandatory:

- treatments prior to sedation are continued, adapting them to parenteral administration if applicable; occurrence of adverse effects is monitored for dose adjustment;
- intravenous or subcutaneous opioid analgesics (syringe pump, continuous flow pump with option of bolus, repeated injections) are prescribed in the case of spontaneous or care-induced pain; the onset of signs of overdose (respiratory depression, myoclonus) requires a dose adjustment.

► Artificial hydration and nutrition

Artificial hydration and nutrition are treatments that should be stopped in order to avoid the increase of potentially distressing symptoms for the patient.

This can raise a psychological or cultural problem for friends and family or caregivers.

They should be informed that:

- hydration and nutrition needs are reduced at end of life;
- mouth care is routine and reduces the feeling of thirst;
- continuing hydration can result in discomfort (oedema and effusion, increased salivary, bronchial and digestive secretions).

If, despite these explanations, the patient or friends and family wish to continue hydration, it will be kept at a low volume (250 mL/24 hours in adults), except in case of serious adverse effect (congestion, etc.).

4.2.4 Support measures

Care to maintain the patient's comfort is continued or initiated, respecting his/her physical and moral integrity:

- mouth care;
- personal hygiene and comfort care, after injection of opioids if necessary;
- monitoring and rotation of subcutaneous or intravenous injection sites;

[18] http://www.sfetd-douleur.org/sites/default/files/u3/echelle/ecpa_echelle.pdf

[19] *Margaret L. Campbell, Ph.D., R.N., F.A.A.N., Thomas Templin, Ph.D., and Julia Walch, R.N., M.S.N., F.N.P. A Respiratory Distress Observation Scale for Patients Unable To Self-Report Dyspnea, Journal of Palliative Medicine, Volume 13, Number 3, 2010*

- prevention and monitoring for onset of pressure ulcers, wound dressing;
- verification of lack of urinary retention, with possible placement of a urinary catheter;
- monitoring of infusions, if they are continued;
- monitoring of onset of rales;
- monitoring for signs of discomfort, etc.

The physician, care team and friends and family can continue to speak to the patient, even while he/she is under sedation, and to explain to the patient the care he/she will receive.

The presence of volunteers may be proposed.

5. Support for friends and family

Friends and family of the patient under sedation can experience intense distress.

At a hospital and at EHPAD:

- visiting hours will be extended as much as possible, especially for children and for parents of a hospitalised child, with the option of sleeping on site (in the room or nearby). A quality environment will be maintained or proposed to support the friends and family (flowers, telephone, even furniture, etc.);
- professionals meet with friends and family very often, preferably in pairs (physician, nurse or psychologist), in a dedicated place;
- a silent presence may also allow friends and family to confide spontaneously.

At home, the exhaustion of friends and family in permanent contact with the patient must be mitigated to the extent possible by:

- the availability of the medical and medico-social team, with support of the community palliative care team, EMSP, ERRSPP, HAD;
- proposed assistance from volunteers.

This support is based on the following:

- professionals are a source of listening and caring: listening to physical and psychological feelings (fears, feelings of guilt, anger, etc.);
- they advise friends and family about how to continue to help the patient (talking, touch, mouth care, music or reading to promote the atmosphere the patient likes, etc.); they regularly inform friends and family about the patient's condition, the course of the situation, possible changes, and, when the time comes, the approach of death and what is expected in the moments preceding it;
- they provide reassurance, if needed, about the fact that in this context sedation is the only way to keep the patient from suffering;
- they propose the option of receiving social, psychological or spiritual support.

Depending on the situation, the professionals may also:

- tell friends and family about patient or grief counselling associations that have dedicated discussion groups;
- propose the support of a religious representative.

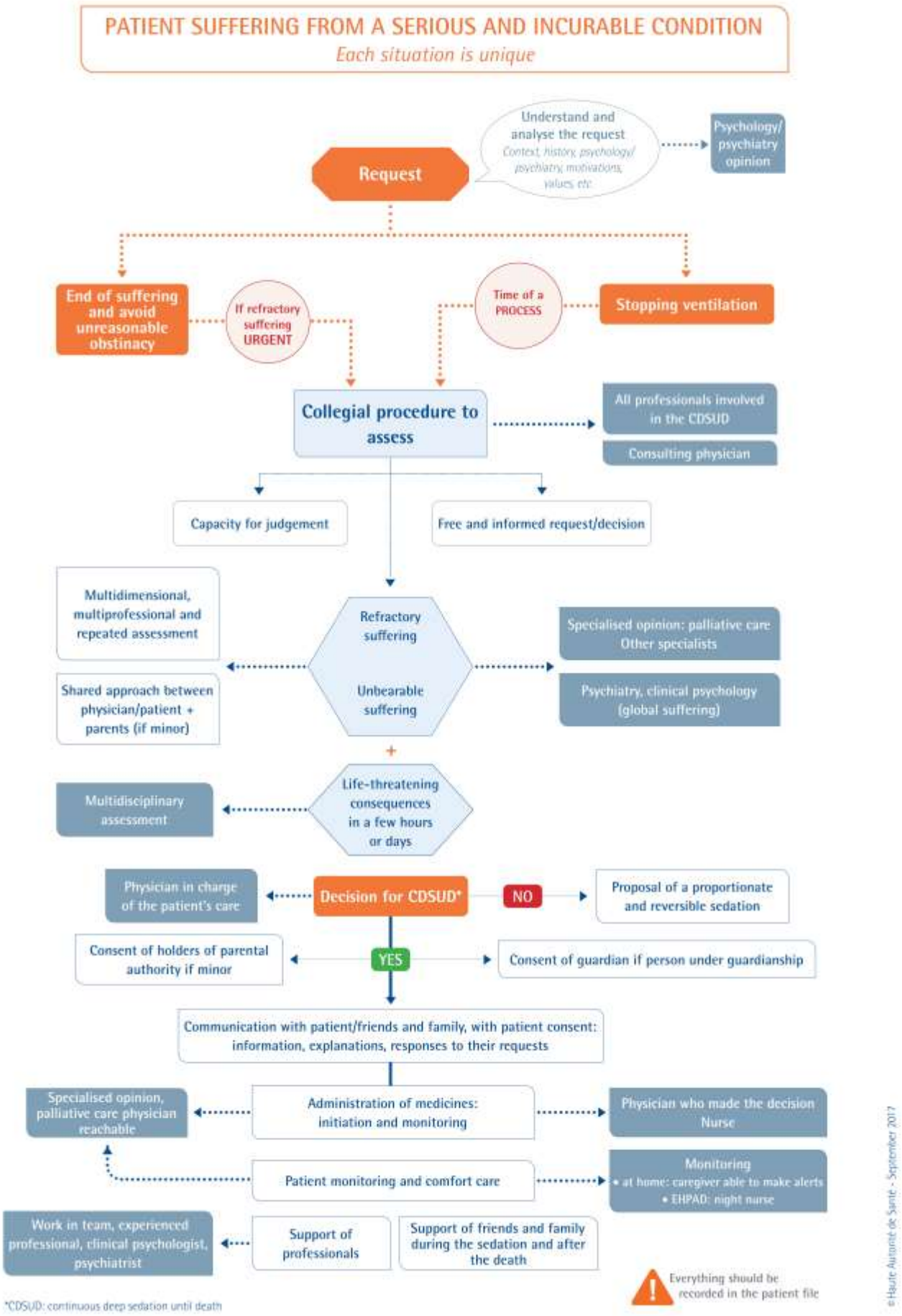
This support will continue until the patient's death.

6. Support for professionals

Sedation of a patient can be cause the professionals to suffer, especially if there is disagreement about the appropriateness of sedation, when the process is prolonged and when children are sedated.

Suffering can be eased by the following:

- have the entire care team participate in the process leading to the decision: all participants should understand the reasons for the sedation and the care objectives; the difference from euthanasia should be explained: CDSUD responds to extreme suffering and not to a request for euthanasia, it does not lead to death;
- identify and assess within the team the suffering of caregivers in each context of CDSUD;
- after the patient's death, have a debriefing meeting to allow the care team to talk about the situation; caregivers should be able to express themselves and talk about their distress regarding this situation;
- promote forums for discussion (discussion group, analysis of practices, ethical reflection group, etc.) led by an experienced professional who is, if possible, from outside of the service: inviting them to express themselves and to share brings forth individual and group problems in relation to the situation;
- request the assistance of a psychiatrist or clinical psychologist with the possibility of referral to individual treatment.


PATIENT SUFFERING FROM A SERIOUS AND INCURABLE CONDITION
Each situation is unique
Request
Understand and analyse the request
Context, history, psychology/psychiatry, motivations, values, etc.
Psychology/psychiatry opinion
End of suffering and avoid unreasonable obstinacy
If refractory suffering URGENT
Time of a PROCESS
Stopping ventilation
Collegial procedure to assess
All professionals involved in the CDSUD
Consulting physician
Capacity for judgement
Free and informed request/decision
Multidimensional, multiprofessional and repeated assessment
Refractory suffering
Unbearable suffering
Specialised opinion: palliative care
Other specialists
Shared approach between physician/patient + parents (if minor)
Psychiatry, clinical psychology (global suffering)
+
Multidisciplinary assessment
Life-threatening consequences in a few hours or days
Physician in charge of the patient's care
Decision for CDSUD*
NO
Proposal of a proportionate and reversible sedation
Consent of holders of parental authority if minor
YES
Consent of guardian if person under guardianship
Communication with patient/friends and family, with patient consent: information, explanations, responses to their requests
Specialised opinion, palliative care physician reachable
Administration of medicines: initiation and monitoring
Physician who made the decision
Nurse
Patient monitoring and comfort care
Monitoring
• at home: caregiver able to make alerts
• EHPAD: night nurse
Work in team, experienced professional, clinical psychologist, psychiatrist
Support of professionals
Support of friends and family during the sedation and after the death
Everything should be recorded in the patient file
*CDSUD: continuous deep sedation until death
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Focus 1. List and accessibility of palliative care professionals

At home or at EHPAD

- Professionals involved in the monitoring of the patient receiving palliative care at his/her residence[20]:
  - community palliative care team, hospital palliative care support team (EMSP);
  - regional paediatric palliative care support team (ERRSPP);
  - community palliative care team or community team skilled and experienced in palliative care;
  - hospital at home (HAD) should have a skilled palliative care team (if not, contact the community palliative care team).
- Palliative care team of the hospital where the patient was monitored or hospitalised;
- If the resources mentioned above are both unavailable, physician from the geographically closest palliative care unit (PCU).

At a healthcare organisation

EMSP, ERRSPP if available, community palliative care team, contact or geographically closest palliative care unit (PCU).

For children: ERRSPP

Accessibility

Palliative care facilities (community palliative care team, EMSP, ERRSPP, PCU) are listed in a directory available on the SFAP website: http://www.sfap.org/annuaire pending the availability of a directory of palliative care facilities accessible 24 hours a day. Territory-based support platforms[21] (available from the regional health agency [ARS]) may, if applicable, make referrals to skilled professionals.

These facilities can make referrals to a psychiatrist or psychologist with experience in end-of-life care (accessible in particular via community palliative care teams or HAD).

[20] *See key points guide "How to promote home care for adult palliative care patients?" http://www.has-sante.fr/portail/upload/docs/application/pdf/2016-07/fpc_sp_a_domicile__web.pdf*

[21] *https://www.legifrance.gouv.fr/eli/decret/2016/7/4/AFSH1615842D/jo*

Focus 2. Conditions of the collegial procedure

► Deliberative process

- The patient is at the centre of the decision-making process: he/she makes the choices concerning his/her end of life or if he/she is unable to decide, his/her substitute decision maker, authorised representative, or friends and family are consulted.
- The end-of-life collective deliberation process involves three major steps:
  - individual: each participant constructs his/her reasoned opinion based on the information collected about the patient and his/her condition;
  - group: participants discuss and debate amongst themselves, which allows comparative and complementary views;
  - conclusive: the decision is made.

► Role of the participants

- Each participant strives to be as objective as possible by analysing his/her motivations, taking into account subjectivity (his experience, his/her representations and projections) and his/her personal frame of reference (ethical, philosophical, spiritual, etc.).
- Each participant should present his/her reasoned opinion based on facts:
  - concerning the condition and the medical status (diagnosis, prognosis, possibilities of improvement, etc.);
  - concerning the patient's situation: quality of life, personal references, friends and family/environment, living conditions, etc.
- The physician in charge of the patient's care:
  - selects the consulting physician: there should be **no hierarchical connection** between the physician in charge of the patient's care and the consultant;
  - specifies the conditions before exchanges and discussion: he/she establishes the practical conditions of the meeting (place, number of participants, planned encounters, etc.), determines the time frame, designates the participants and specifies their role and their obligations (rapporteur, "meeting secretary", coordinator/moderator, etc.);
  - makes the decision alone after the collegial procedure.
- Paramedical professionals, pharmacist: in contact with the patient or family, their role is essential because they have extensive knowledge about the patient: his/her living environment, history, convictions, feelings and those of his/her friends and family.
- The "consulting" physician: he/she has knowledge, experience and, since he/she **does not directly participate in the patient's care**, he/she has the perspective and impartiality required to verify that the situation has been assessed in its entirety. Through a clear analysis of the situation, he/she **offers an informed opinion.** Through an exchange with a colleague, he helps the practitioner who consulted him/her to bring to a conclusion on the interests of the patient.

► Course of the meeting

The collegial procedure requires a meeting. Although the presence of all of the participants mentioned may be difficult at home or at EHPAD, the infrequency of this situation, the potential difficulty of assessment and the issue of collective deliberation make it essential. When the physical presence of some participants is impossible (consulting physician, etc.), other means may allow them to participate: teleconference, video conferencing, etc.

Several meetings may be required if this does not delay implementation of appropriate means to provide relief to the patient.

It should be carried out according to ethical rules of deliberation:

- encourage free expression of all parties: everyone's opinion is requested with care and respect;

- respect another's turn to speak, listen without interrupting;
- do not pass judgement;
- give a reasoned opinion.

Consensus is not required by French law. A third physician may be consulted if one of the two physicians deems it useful (preferably with no hierarchical connection and not necessarily present at the meeting).

Consulting a clinical ethics committee may provide additional insights.

At the end of the meeting, a collective opinion is given and room is left to note diverging opinions. This opinion is then formalised and recorded in the file.

► After the collegial procedure

The decision belongs **solely to the physician** in charge of the patient; the deliberation time may be separate from the time of the decision. The decision is announced:

- to the care team that participated in the deliberation and that is charge of the patient's care;
- to all participants in the process.

The reason for use (or not) of sedation is announced:

- to the patient;
- to the substitute decision maker or, failing that, the family or a friend if the patient is unable to express his/her wishes.

This decision should be formalised in the file, describing the reasons for the decision.

The following is also recorded:

- names and positions of persons consulted;
- patient's request for implementation of continuous deep sedation;
- steps of the this procedure;
- basis of the physician's decision;
- in the case of a patient who cannot express his/her wishes and for whom the decision is made to stop life-sustaining treatments: the wishes expressed by the patient in advance directives or, if there are no such directives, testimony of the wishes expressed by the patient, collected from the substitute decision maker or, failing that, from the family or a friend;
- information given to the patient and to friends and family (by whom, to whom and when?).

At a healthcare organisation, the opinion of the patient's treating physician consulted is recorded.

► Assessment

Retrospective assessment of the course of the deliberative process allows the care team to move forward and to be better able to respond to similar situations. Maintaining a written record of the course of the collegial procedure may be useful to the team involved.

Focus 3. Assessment of the refractory nature of suffering or of the patient's decision to stop a treatment, resulting in life-threatening consequences

Table 3. Assessment in a patient who requests to avoid any suffering and unreasonable obstinacy

Aspects to consider
Clinical data: ■ the condition: incurable, in terminal phase ■ physical symptoms: ineffectiveness, delayed action and adverse effects of treatments carried out and treatments proposed ■ mental symptoms: anxiety, depressive symptoms, anxiety about death, demoralisation, suicidal thoughts
Other causes of suffering: ■ social/family factors: isolation, feeling of being a burden to others, loss of social support or social role, family burden ■ psychological distress: intense negative emotional experience, fear of pain, the disease or circumstances surrounding death, loss of autonomy, successive bereavements, identity suffering, anger, sadness, disappointment, low self-esteem, etc. ■ spiritual suffering (existential or religious): loss of meaning, hope or plans, loss of bearings, feelings of loss of dignity, loneliness, feelings of abandonment, etc.
The underlying intent of the request: ■ not to die in pain or to die without pain ■ wish to hasten death[22] ■ wish to control when and how to die
Information given to the patient, comprehension of the information received and of CDSUD: ■ clarify of the information provided, lack of inconsistencies, ambivalence ■ comprehension of the information: rephrasing, comprehension of the family ■ comprehension of the risk/benefit ratio, existence of alternatives (in particular proportionate, reversible sedation)

[22] Definition of WTHD (wish to hasten death): "The wish to hasten death is a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his/her death. This wish may be expressed spontaneously or after being asked about it. It must be distinguished from the acceptance of impending death or from a wish to die naturally, although preferably soon.

The WTHD may arise in response to one or more factors: physical symptoms (present or anticipated), psychological distress (depression, hopelessness, fears, etc.), existential suffering (e.g. loss of meaning in life), or social aspects (feeling that one is a burden, etc.)".

Focus 4. Administration of midazolam

In adults

Intravenous (IV) administration is preferred over subcutaneous (SC) administration; the placement of a pump with option of bolus facilitates dose adjustments.

Two methods of IV administration are possible:

- a loading dose, administered by titration[23], followed by a maintenance dose:
  - the loading dose allows the patient to fall asleep quickly, often a bad experience for the caregivers; it does not allow the maintenance flow to be predicted,
  - the Summary of Product Characteristics (SPC)[24] of midazolam in the intensive care unit recommends 1 mg over 30 seconds every 2 minutes,
  - in a very elderly or weak patient, the injections will be done every 5 minutes,
  - injections are continued until a score of -4 to -5 on the Richmond Agitation-Sedation Scale or a score of 5 on the Rudkin scale (Appendix 3, Table 4) is achieved; the total dose required to induce sedation is recorded in the file,
  - the recommendations of the French Healthcare Product Safety Agency (AFSSAPS) and the SFAP[25] recommend an hourly maintenance dose equal to 50% of the dose required to obtain a score of 4 on the Rudkin scale, for reference, in continuous infusion; this dose may be insufficient in case of CDSUD and should be adjusted according to the regimen below;
- a maintenance dose from the start, to be gradually increased, without loading dose:
  - it causes the patient to fall asleep more slowly,
  - the SPC of midazolam in the intensive care unit recommends a dose of 0.03 mg/kg/h to 0.2 mg/kg/h, and this dose will be reduced in elderly or weak patients,
  - this dose will be adjusted by increments of 0.5 mg/h every 20 minutes to 2 hours until a score of -4 to -5 on the Richmond Agitation-Sedation Scale or 5 on the Rudkin scale is achieved.

For subcutaneous administration, titration of the loading dose is not possible: a dose of about 0.1 mg/kg can be done (to be reduced in elderly or weak patients). Maintenance is done at the same doses as in IV administration.

Dose adjustment:

- a dose increase may be necessary to maintain sedation after a prolonged use (tachyphylaxis);
- in case of awakening, IV boluses of 1 mg over 30 seconds every 2 minutes may be administered.

In children

In addition to the intravenous administration (preferred) and subcutaneous administration, midazolam can be administered in continuous enteral administrative via nasogastric tube or gastrostomy; intra-rectal administration, though easy to use, does not appear to be suitable for continuous sedation.

[23] *Titration is the repeated use of bolus to achieve the desired degree of sedation without inducing any significant adverse effects.*

[24] *http://agence-prd.ansm.sante.fr/php/ecodex/frames.php?specid=65358251&typedoc=R&ref=R0234533.htm*

[25] *http://ansm.sante.fr/var/ansm_site/storage/original/application/0f8ed3dd2a116934a6fe38cf56367eb8.pdf*
http://www.sfap.org/system/files/sedation-phase-terminale.pdf

Two methods of administration are possible:

- a loading dose (by titration), followed by a maintenance dose:
  - do a slow IV injection (over a few minutes) of 30 µg/kg every 5 minutes without exceeding 1 mg per injection, until a score of -4 to -5 on the Richmond Agitation-Sedation Scale or 5 on the Rudkin scale is achieved,
  - record the number of milligrams required for induction,
  - maintain the sedation by administering via continuous intravenous infusion an hourly dose equal to 50% of the dose used for induction,
  - alternatively, the maintenance dose may be administered discontinuously, by intravenous or subcutaneous administration, or by a gastric tube or gastrostomy. In this case, breakthrough doses must be provided during the first prescription;
- a maintenance dose from the start, to be gradually increased, without loading dose:
  - start with a continuous intravenous dose of 0.02 to 0.03 mg/kg/h,
  - increase by increments of 0.02 to 0.03 mg/kg/h every 3 to 6 hours until a score of 5 on the Rudkin scale is achieved.

However, these dosages described in children are variable: they should be adjusted to the situation and may, in particular, be increased.

In adults and children, the possibility of an awakening, especially during care or nursing, is anticipated by the one-time injection of a supplemental dose of analgesic and sedative.

Appendix 1. Regulatory and legislative texts

1. Extract from the French Law of 2 February 2016 creating new rights for patients and the terminally ill

Article 2

Art. L. 1110-5-1. –"The procedures mentioned in article L. 1110-5 should not be implemented or continued when they result from unreasonable obstinacy. When they appear useless or disproportionate or when they have no effect other than artificially maintaining life, they may be interrupted or not implemented, according to the wishes of the patient and, if the patient is unable to express his/her wishes, at the end of a collegial procedure defined by regulations.

"Artificial nutrition and hydration constitute treatments which can be stopped in accordance with the first paragraph of this article.

"When the procedures mentioned in the first two paragraphs of this article are stopped or not implemented, the doctor safeguards the dignity of the dying person and ensures his/her quality of life by providing the palliative care mentioned in Article L. 1110-10."

Article 3

Art. L. 1110-5-2.- "At the request of the patient to avoid any suffering and unreasonable obstinacy, a continuous deep sedation bringing about an altered state of consciousness to be continued until death, combined with analgesia and stopping of all life-sustaining treatments, shall be implemented in the following cases:

"1. When a patient suffers from a serious and incurable condition which is life-threatening in the short term and the patient has pain that is refractory to treatment;

"2. When the decision of a patient suffering from a serious and incurable condition to stop treatment has life-threatening consequences in the short term and could lead to unbearable suffering.

"When the patient cannot express his/her wishes and, in keeping with the right to refuse unreasonable obstinacy mentioned in Article L. 1110-5-1, in the case where the physician stops life-sustaining treatment, the physician administers continuous deep sedation bringing about an altered state of consciousness to be continued until death, combined with analgesia.

"The continuous deep sedation combined with analgesia mentioned in this Article shall be implemented according to the collegial procedure defined by regulations and which allows the care team to check in advance that the conditions for implementation established in the preceding paragraphs have been met.

"At the request of the patient, continuous deep sedation can be implemented at his/her home, at a healthcare organisation or at an establishment mentioned in paragraph I, number 6 of Article L. 312-1 of the Family and Social Action Code (CASF)[26].

"The entire procedure followed is recorded in the patient's medical file."

Article 4

[26] *Paragraph I, number 6 of Article L. 312-1 of the CASF: "Establishments and departments that receive elderly persons or provide them with home-based assistance in activities of daily living, provision of care or social support".*

Art. L. 1110-5-3.- "Every person has the right to receive treatments and care aimed at relieving his/her suffering. This must, in all circumstances, be anticipated, taken into consideration, assessed and treated.

"The physician implements analgesic and sedative treatments necessary to treat the refractory suffering of a patient at an advanced or terminal stage, even if they may have the effect of shortening the patient's life. The doctor informs the patient, without prejudice to paragraph 4 of Article L. 1111-2, the substitute decision maker provided for in Article L. 1111-6, the family, or failing that, a friend of the patient. The procedure followed is noted in the medical file.

"Every person is informed by the healthcare professionals of the possibility of home care, as long as his/her condition allows it."

Article 5

L. 1111-4 (…) "Every person has the right to refuse or to not receive a treatment. However, the patient continues to be monitored by the physician, especially his/her palliative care.

(…) "The doctor is required to respect the wishes of the person once that person has been informed of the consequences of his/her choices and of their seriousness. If, through his/her wish to refuse or to discontinue treatment, the person puts his/her life in danger, he/she must reiterate that decision within a reasonable time frame. The person may call on another member of the medical staff. The entire procedure is recorded in the patient's medical file. The doctor safeguards the dignity of the dying person and ensures the quality of his/her end of life by providing the palliative care mentioned in Article L. 1110-10." (…)

2. Extracts from the Decree of 3 August 2016 amending the code of medical ethics, and on collegial procedures and the use of continuous deep sedation until death provided for by the French Law of 2 February 2016

Art. R. 4127-37.- "In all circumstances, the physician shall relieve the suffering of the patient by methods appropriate for the patient's condition and shall provide moral support. The physician shall refrain from all unreasonable obstinacy and can refuse to implement or to continue treatments which appears useless, disproportionate or which have the sole effect of artificially maintaining life."

Art. R. 4127-37-2.-I. (…) III. (…) This collegial procedure takes the form of a dialogue with the members present from the care team, if it exists, and the reasoned opinion from at least one physician, called on as a consultant. There should be no hierarchical connection between the physician in charge of the patient and the consultant. The reasoned opinion of a second consultant may be collected by the first two physicians if either of them considers it necessary."

Art. R. 4127-37-3.-I. "At the request of the patient, in the situations provided for by numbers 1 and 2 of Article L. 1110-5-2, continuous deep sedation causing an altered state of consciousness until death combined with analgesia and the stopping of all forms of life-sustaining treatment, may be implemented after the collegial procedure, as defined in III of Article R. 4127-37-2. The aim of this collegial procedure is to ensure that all the conditions established by law have been met."

"Use, at the request of the patient, of continuous deep sedation as defined in the preceding paragraph, or its refusal, must be reasoned. The reasons for the use or non-use of such sedation are recorded in the patient's medical file and he/she is informed of them."

"II. When the patient is not in a position to express his/her wishes and a decision has been made to end life-sustaining treatment in order to avoid unreasonable obstinacy, in application of Articles L. 1110-5-1, L. 1110-5-2 and L. 1111-4 and in the conditions established by this Article, the physician in charge of the patient, even if the suffering endured by the patient cannot be assessed due to the patient's cerebral state, may implement continuous deep sedation causing an altered state of consciousness until death combined with analgesia, unless the patient personally opposed this in his/her advance directives.

The decision to use continuous deep sedation, thus defined, must, in the absence of opposition expressed by the patient in advance decisions, be made according to the collegial procedure established in Article R. 4127-37-2.

“In the absence of advance directives, the physician in charge of the patient will gather testimony of the wishes expressed by the patient from the substitute decision maker or, failing that, from the family or a friend.

“Use of continuous deep sedation must be reasoned. The patient’s wishes expressed in the advance directives or, if there are no advance directives, the testimony of the wishes expressed by the patient gathered from the substitute decision maker support or, failing that, from the family or a friend, as well as the opinions gathered and the reasons behind the decision are all recorded in the patient’s medical file.

“The substitute decision maker or, failing that, the family or a friend of the patient is informed of the reasons for use of continuous deep sedation.”

These articles appear in the Public Health Code, which was amended (Articles L. 1110-5 et seq., Articles R. 4127-37 to R. 4127-37-4).

3. Extracts from the code of medical ethics

Article 37-3 (Article R. 4127-37-3 of the Public Health Code)

Use, at the request of the patient, of continuous deep sedation as defined in the preceding paragraph, or its refusal, must be reasoned. The reasons for the use or non-use of such sedation are recorded in the patient’s medical file and he/she is informed of them.

II.- When the patient is not in a position to express his/her wishes and a decision has been made to end life-sustaining treatment in order to avoid unreasonable obstinacy, in application of Articles L. 1110-5-1, L. 1110-5-2 and L. 1111-4 and in the conditions established by Article R. 4127-37-2, the physician in charge of the patient, even if the suffering endured by the patient cannot be assessed due to the patient’s cerebral state, may implement continuous deep sedation causing an altered state of consciousness until death combined with analgesia, unless the patient personally opposed this in his/her advance directives.

The decision to use continuous deep sedation, thus defined, must, in the absence of opposition expressed by the patient in advance decisions, be made according to the collegial procedure established in Article R. 4127-37-2.

In the absence of advance directives, the physician in charge of the patient will gather testimony of the wishes expressed by the patient from the substitute decision maker or, failing that, from the family or a friend.

https://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000031970253&categorieLien=id

https://www.legifrance.gouv.fr/eli/decret/2016/8/3/AFSP1616790D/jo/texte

https://www.conseil-national.medecin.fr/sites/default/files/codedeont.pdf

Appendix 2. Palliative Performance Scale

Victoria Hospice

Palliative Performance Scale (PPSv2) version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Instructions for Use of PPS (see also definition of terms)

1. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.
2. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

   Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

   Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

   Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'
3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.
4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

Palliative Performance Scale (PPSv2) version 2. *Medical Care of the Dying, 4th ed.*, p. 120. ©Victoria Hospice Society, 2006.

Victoria Hospice

Palliative Performance Scale (PPSv2) version 2

Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

1. Ambulation
The items '**mainly sit/lie**,' '**mainly in bed**,' and '**totally bed bound**' are clearly similar. The subtle differences are related to items in the self-care column. For example, 'totally bed 'bound" at PPS 30% is due to either profound weakness or paralysis such that the patient not only can't get out of bed but is also unable to do any self-care. The difference between 'sit/lie' and 'bed' is proportionate to the amount of time the patient is able to sit up vs need to lie down.

'**Reduced ambulation**' is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.

2. Activity & Extent of disease
'**Some**,' '**significant**,' and '**extensive**' disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, 'some' may mean the shift from HIV to AIDS, 'significant' implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. 'Extensive' refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.

The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (eg. trying to walk the halls).

3. Self-Care
'**Occasional assistance**' means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

'**Considerable assistance**' means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.

'**Mainly assistance**' is a further extension of 'considerable.' Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

'**Total care**' means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

4. Intake
Changes in intake are quite obvious with '**normal intake**' referring to the person's usual eating habits while healthy. '**Reduced**' means any reduction from that and is highly variable according to the unique individual circumstances. '**Minimal**' refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

5. Conscious Level
'**Full consciousness**' implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. '**Confusion**' is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. '**Drowsiness**' implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. '**Coma**' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

Palliative Performance Scale (PPSv2) version 2. *Medical Care of the Dying, 4th ed.*; p. 121. ©Victoria Hospice Society, 2006.

Appendix 3. Sedation scale

Table 4. Rudkin Scale

Score	Sedation level
1	Patient fully awake
2	Patient drowsy
3	Patient with eyes closed, but wakes on demand
4	Patient with eyes closed, but wakes with light physical stimulation
5	Patient with eyes closed who cannot be woken with light physical stimulation

http://www.sfap.org/system/files/sedation-phase-terminale.pdf

Appendix 4. Example of monitoring and communication log

First name	Surname
Primary diagnosis:	
Comorbidities, other noteworthy symptoms	
Indication for sedation	
Date of start of sedation: (day/month/year) ——/——/————	Time:

Date	Time	Richmond or Rudkin Scale	Algoplus Scale or ECPA* or other pain scale	RDOS*	Pulse	Medicine(s) administered/route of administration	Total loading dose (mg)	Maintenance rate (mg/h)	Supplemental bolus (mg)	Check the syringe pump every 8 to 12 hours	Other comments Adverse effect	Initials

Date	Time	Richmond or Rudkin Scale	Algoplus Scale or ECPA* or other pain scale	RDOS*	Pulse	Medicine(s) administered/route of administration	Total loading dose (mg)	Maintenance rate (mg/h)	Supplemental bolus (mg)	Check the syringe pump every 8 to 12 hours	Other comments Adverse effect	Initials

** ECPA: Évaluation comportementale de la douleur chez la personne âgée [Behavioural assessment of pain in the elderly], RDOS: Respiratory Distress Observation Scale*

Adapted from “La sédation palliative en fin de vie” [End-of-life palliative sedation], Collège des médecins du Québec, Société québécoise des médecins de soins palliatifs. Montréal: CMQ; 2016.

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Association francophone pour les soins oncologiques de support, Association des coordinateurs de réseaux de cancérologie, Société française de psycho-oncologie, Union nationale des réseaux de santé. Refus de soin en oncologie chez l'adulte. Référentiels inter régionaux en Soins Oncologiques de Support. Bègles: AFSOS; 2014. http://www.sfpo.fr/images/refus_de_soins_AFSOS_-_SFPO.pdf

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