End-of-life
Dealing with emotions

The emotions of those nursing the terminally ill, for a long time neglected or even denied, are now given greater expression. Acknowledging these emotions helps nurses to avoid exhaustion in the long term and improves the carer-patient relationship. Nevertheless, without outside assistance, it will always be difficult to strike a balance between too much and not enough emotional involvement.

Valérie Mayer, a private nurse in the Ain département in France, clearly recalls the words of her college teachers in the early 1990s: "There is no need for emotions. Make sure you don't let anything upset you." Not that long ago, the nursing college could still brush aside the feelings of nurses, or simply ignore them. As a nursing student, Valérie Faure, who graduated in 2002 in Montpellier, had never heard any mention of the emotional experiences of carers. "Or of patients for that matter", she complains. Teaching has evolved only recently. Emotional management has been part of the curriculum of the Instituts de formation en soins infirmiers (Ifsi, nursing institutes) since 2009. "Teachers are obliged to talk about it", underlines Catherine Mercadier, sociologist and Director of the Ifsi-Ifas(1) of the Centre hospitalier de Montauban in Tarn-et-Garonne. "Emphasis has been laid on practice analysis", adds Pascal Prayez, who is a doctor of clinical and social psychology and has thought a lot about how nurses can keep the right distance. "Based on a dialogue, for example, we ask students to identify the defence mechanisms used by the carer and to imagine alternatives to this reaction."

Nursing students' habits have also changed. They express their feelings more easily than their elders, breaking the silence which for a long time surrounded how health professionals cope with patients reaching the end of their lives and dying. In her thesis on the emotional work of carers in hospital, published in 2002(2), Catherine Mercadier makes the following observation: "All the emotions felt by carers during interaction with the patient are euphemised, if not denied, because they are not allowed." Carers are torn between their "sentimental reality and the professional norm allowed, or even required". Today, "the norm created by the group still exists, but the boundaries are moving a little", remarks the sociologist. "Professional culture is being greatly influenced by social culture, in which emotions are expressed much more easily than they were ten or 20 years ago."

REPRESSING YOUR EMOTIONS IS FUTILE

If carers are denied the right to feel, it is also in the name of professionalism. "One of the cultural characteristics of the carer is to deny any vulnerability in the face of adversity: 'You must be strong to support those who are weakened by illness'", points out psychologist Séverine Gaudron in the collaborative work Distance professionnelle et qualité du soin(3). "The good carer is very close to emotional neutrality, without being completely neutral, in which case they would be accused of coldness or indifference", analyses Catherine Mercadier in her thesis. However, trying to harden oneself always ends in failure. "Denying your emotions stops you from dealing with them properly", she
points out. "After a while, a carer facing emotionally difficult situations becomes professionally exhausted or reacts aggressively, through spiteful behaviour." Denying one's emotions "will lead to mechanical practices, void of empathy", regrets Françoise Ellien, Director of the Spes network of palliative care in southern Essonne and psychologist/psycho-analyst. "But that doesn't mean that you must be overflowing with love in order to support people."

**PRIVATE NURSES, FREER BUT LONELIER**

Facing the end of life and death arouses a wide range of emotions, of which the carer is more or less aware: he might feel fear at the idea of dying himself or losing loved ones; he might be saddened by seeing a patient with whom he had established an emotional relationship pass away; he might feel disgusted by repulsive wounds; he can be overcome by feelings of injustice and revolt vis-à-vis the premature death of children; he may feel guilty that he does not have enough time to spend with the dying person ... Unlike hospital nurses, private nurses have a certain amount of freedom of action and expression. "We have no superiors above us or colleagues from whom we have to hide for fear of being judged", compares Valérie Mayer, who started her career as an intensive care nurse before choosing to work as a private nurse in 1999. "Each person can cope with death in their own way. Some need to focus on post-mortem care to say goodbye to the person and some don't want to do this, and use the services of a funeral parlour", says Anne Jacquet, private nurse in Toulouse and a trainer in institutes and with nursing teams. Those who so wish are free to attend the burial, whereas others may prefer not to." But private nurses can suffer from severe loneliness in such trying times. "Some practices work well as a team but many private nurses experience death alone, with no one to talk to", continues Anne Jacquet. "Being alone is very difficult", confirms Valérie Faure, a private nurse in Lattes close to Montpellier. "When you find a 90 kg patient dead in his bed, in his own excrement, you have to handle the situation despite your shock. Yet you cannot do everything yourself, such as lifting him and putting him in a dignified position. I have often worked together with the emergency services."

**RECHARGING THE BATTERIES**

In order to cope, private nurses have developed their own strategies. The car transporting you from one home to another is a place for letting off steam. Sometimes the patients themselves unwittingly help nurses to recharge their batteries. "We spend all our energy on end-of-life patients and draw strength from all the others, those with broken legs, the grandmothers who need us to put on their tights, those who annoy us for a little cut which they think will kill them", says Annie Pivot, a private nurse in Civrieux-d'Azergues near Lyon. She chose to put many of her emotions as a nurse down on paper. She is the author of *Les pains au lait du lundi et autres gourmandises*(4), in which she talks about her job, the laughter and the tears. Others unwind through sport, get rid of tensions through relaxation, or distract themselves by getting involved in theatre or music. "Due to the frantic pace of nursing work and the emotional burden of contact with end-of-life patients, nurses often have their noses to the ground and sometimes feel out of breath", observes psychologist Séverine Gaudron. "They need to get a second wind to avoid suffocation, and be able to free up some time for themselves, even just half an hour a week."
SUPPORT FROM NETWORKS

Beyond the leisure and moments of fun which we allow ourselves, talking about our emotions generally makes it easier to cope with hard times and to keep the right distance. This distance varies depending on the carers, patients, families of patients and care situations. In private nursing, palliative care networks can be used to release one's emotions by talking. "Nurses often call about a technical issue and then, gradually, when they feel safe, they end up saying that they are having a hard time or are suffering", observes Marie-Claude Daydé, a private nurse in Colomiers in Haute-Garonne and a member of the support team in the palliative care pain network in Toulouse. These networks sometimes have discussion groups, but it is rare. At the start 11 years ago, the Spes network in Ile-de-France had set up a discussion group on a set day and time for private nurses to encourage them to put their feelings into words. "We noticed that this was an unsuitable arrangement", recounts the Director of the Spes network, Françoise Ellien. "Discussion groups which are not organised regularly but rather at specific stages in the care of a patient seem closer to meeting private carers' expectations." On a case-by-case basis, the network can therefore organise occasional discussions between a psychologist, one or more nurses, the general practitioner, and even the patient's close relations. "We try to work through the difficulties experienced by nurses at that time", continues Françoise Ellien. The network can also offer nurses meetings at the end of the care provided. "Alternatively, I can see the nurse on a one-to-one basis if her emotional burden is linked to more personal experiences being revived."

TRAINING AND SELF-EXAMINATION

In his search for the right professional stance, the nurse faces two stumbling blocks: "involvement without distance" and "distance without involvement", in the words of Pascal Prayez, a doctor in clinical and social psychology. Although there is no predetermined appropriate distance, the nurse can count not only on exchanges with peers and support from palliative care networks, but also ongoing professional training in order to improve their ability to care for the terminally ill. Valérie Mayer, private nurse in Saint-Etienne-du-Bois in the Ain region, in fact decided to spend the last few years studying the care relationship, empathetic touch and even reflexology. She had been showing signs of fatigue and weariness: "After a while, when you accompany people and have no training, you exhaust yourself", she remarks, speaking from experience. Setting aside some time to take ongoing professional development modules can be healthy. Working on yourself can also be useful. "This makes it possible to identify your own emotions in order to keep them at a certain distance and concentrate better on the patient and what he is going through, rather than on our own projections", encourages Séverine Gaudron, a psychologist. We can start psychotherapy or analytical work, be accompanied by a coach or a clinical nurse or simply think over the issue by reading about it. Lastly, "a good professional is someone who will manage to express his emotions, analysing them in order to better manage them and offer professional and relational availability to the dying person and his entourage", concludes Catherine Mercadier. The question of whether it is unprofessional to cry at the death of a patient is outdated today ...
(1) Training institute for health-care assistants.
(4) Les pains au lait du lundi et autres gourmandises, Annie Pivot, a.m.v.editions, 2010.

**Interview**

Pascal Prayez, doctor in clinical and social psychology, trainer

"Becoming aware of your emotions"

**A few years ago, you deplored the "emotions taboo" in the nursing profession. Are emotions still taboo today?**

That depends on where you work, but there is still a tendency to hammer home the idea that: "you must be professional and avoid the emotional side of things". Yet where there are human relations, there are always emotions. Of course, you should not be overcome by your feelings but being aware of them, acknowledging them, is a key to being professional.

**In contrast to the right distance, what is involvement without distance, or distance without involvement?**

Involvement without distance is, for example, when a carer is invaded by his professional activity 24 hours a day or when he is upset by one particular patient, and cannot take a step back. Since he is personally affected by this person, he feels guilty that he cannot do more, and sometimes he might visit that person even outside working hours. He thinks about them at night, etc. This will be a very difficult position to tolerate in the long term – it almost becomes a private relationship in which the carer sacrifices his professionalism – or if the patient dies, he will suffer as if he was grieving a personal loss. In a bid to avoid such excesses recurring, the carer then might devote himself to strictly technical care, thereby switching to what I call distance without involvement.

**Box 1**

**Account**

"I cannot leave that lady to die like that"

Anne Jacquet, private clinical nurse and trainer in Toulouse (département 31), graduated in 1987

"I was deeply shaken by my first nursing traineeship. In my ward, there was a lady with an acute pulmonary oedema. She was in agony. No one went into her room, not the nurses or the doctor. There was no family around her either. I went with another trainee to see the matron, who told us: "It's just like that, when someone is dying, you say nothing and leave them alone." I said to my colleague: "I can't leave that lady to die like that." We both asked if we could stay with her until she died. It was the first time I
accompanied someone. It was also the first time that I had been confronted with death. She died completely asphyxiated. I was holding her hand. When I returned to college, I didn't talk about it to anyone. That experience determined my career. I have always attached importance to developing the relational dimension in nursing."

Box 2
Analysis
Defence mechanisms
Defence mechanisms are triggered automatically in times of anxiety, powerlessness and uneasiness. In her book *Face à la maladie grave, patients, familles, soignants*, published by Dunod in 1995, Martine Ruszniewski describes the various defence mechanisms used by the carer to adapt to painful or even intolerable situations. We can cite:

- lying in response to the patient's questions
- false reassurance involving keeping the patient in artificial hope
- avoidance, where the carer always avoids talking to the patient about his suffering
- derision, where the carer makes light of what the patient says to him
- trivialisation where, for example, the carer declares to the patient, who is talking about his own mortality: "We all die one day."

"Whether these are defence mechanisms or adaptation strategies, also referred to as coping, the aim is the same: to protect the carer from the aggression suffered in his place of work", writes Séverine Gaudron in *Distance professionnelle et qualité du soin* (Editions Lamarre, 2009). She continues: "In order for the carer to give up these defence methods, he first needs to tackle the sources of his suffering, understand them, listen to them and acknowledge them. It is also necessary to help the carer, to delve into his defence mechanisms with him and acknowledge them as a legitimate response, depending on his psychological condition."

Box 3
Account
"It is the worst thing to see a child die"
Annie Pivot, private nurse in Civrieux-d'Azergues (département 69)

"With my colleague, we looked after a little 5-year-old girl just over a year ago who was suffering from brain cancer. We knew that there really was no effective treatment for her. One day, she collapsed and the doctor said that she was about to die. Her mother called the ambulance to take her to hospital. I was there at the time. I was struck by what was happening around the little girl. I remember her mother's blouse, it was a pale colour. I
saw her heart beating through it when she tried to keep things light for the benefit of the big sister, who must have been 7 or 8 years old. Emotionally, it is the worst thing to see a child die. I was lucky to have had a lot of support from my boyfriend, and he helped me to recover. I also had the support of the team from the Léon-Bérard centre in Lyons, which is available 24 hours a day, and of a private doctor.

**Box 4**

**Emotions on the nursing syllabus**

In the *Institut de formation en soins infirmiers* (Ifsi, nursing care training institute), "various aspects of the emotions are covered in a number of teaching modules", indicates Catherine Mercadier, sociologist and Director of Ifsi-Ifas in the *Centre hospitalier de Montauban* (82). For example, the teachers tackle emotions by adopting a theoretical approach in psychology (UE 1-1 S1). In sociology, they cover the concepts of distance and proximity and the issue of violence in nursing (UE 1-1 S2). In relational care, teachers are asked to guide the analysis of emotions (UE 4-2 S5). Lastly, the feelings and emotions of nurses providing end-of-life support are covered under palliative and end-of-life care (UE 4-7 S5).

**Box 5**

**Find out more**

**JULIE OU L'AVENTURE DE LA JUSTE DISTANCE**

A fictional story to inspire reflection on keeping the right distance in care.

*Pascal Prayez, Editions Lamarre, 2005.*

**LA SOUFFRANCE AU TRAVAIL**

Burn-out applied to nurses: the consequences for the nurse and the patient, advice on taking care of yourself, etc.

*Alexandre Manoukian, Editions Lamarre, 2009.*
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