
Treatment of pain

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Abstract : Anaesthetist, specialist and coach in the treatment of pain, palliative care, and ethical medical practice, shared with us his clinical experience of working with those approaching death, from a Buddhist perspective. At the end of life there is always physical and psychological suffering: this has social, relational and spiritual dimensions. Thus we talk of a “global suffering” which necessitates an individualised approach and the subsequent coordination of all concerned parties. The vocation of accompaniment and palliative care is to relieve suffering and limit its impact on the patient and those close to them. After a description of various traits, psychological and physical, characterising the experience of dying, alongside the different stages passed through by both the dying person and their loved ones O Rabary introduces what, for Buddhism, is the prime importance of the last thought. Sedating the patient in the final phase – in order to relieve him of intense suffering, unresponsive to normal methods – has the undesirable consequence of compromising the clarity of our mental response. It may pose an ethical dilemma. Olivier will discuss how accompanying the dying can help us actualise, make concrete, the Bodhisattva Way. How compassion and listening to the needs of others who suffer is the work of a bodhisattva. O.R makes clear what we mean by euthanasia and medically assisted suicide and the position taken in respect of both by Buddhist ethics. He will talk about Shinjin, the unity of body and mind: how the accompaniment allows us to practice the “Four Unlimited.” Palliative care is not about uselessly prolonging life, but to ameliorate its quality, already present in the sufferer – without willingly hastening it to its end. Death, O.R emphasises, is not just the affair of the dying, it is a social event, a community event that brings together the human family – which, in effect, actualises the state of interdependence that exists between all living beings.

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“There’s nothing to reject in life and death: beyond life and death there is no nirvana to wish for.”

Dogen

He who is dying is, above all, a living being, a being of relations. Even if his capacities are reduced he rests in contact with all around him. It’s within the framework of relations that we can tackle the approach of the end of life. It is artificial to try and separate the dying person from the process of life – as it comes to its end. Buddhism teaches us that life and death exists in continuity with each other. Despite the obvious physical modifications and psychological changes we can see as life closes to its end – which are entirely characteristic of life and deserve, here, to be referred to.

Firstly, I will deal with the transformations of the last phase. Then, we will look at the values thusly engaged and the ethical questions which reveal themselves in this context and I will underline what I see as points of convergence between the practice of accompaniment and the

healing of the Dharma. I will tackle the question of spiritual accompaniment and healing, and finally I will finish with what we call a “clinical vignette” – regarding an experience with the dying, one that will allow me to illustrate my point.

Roland invited me to contribute to this training day for the teachers of the ABZE –because of my experience as a doctor experienced in palliative medicine in the university hospital center. Reading the title for the day I asked myself: “What is a dying person?” If we ask the Littré dictionary is “someone who dies, who carries the signs of impending death.” What are the signs of impending death? As soon as one pushes open the door of a dying person’s room we can see these signs. I will try to describe the traits, both physical and psychological, of the end of life. This will be useful to us, to begin to help, heal and accompany the dying, in the passage to death.

The dying experience in their body and spirit their own finitude. This experience is at once common and utterly unique. Elisabeth Kubler-Ross, a Swiss psychiatrist who has, for a very long time, studied the dying and observed the different psychological stages they go through has seen similar stages in the bereaved who accompany them – stages which are mirrored to a greater or lesser extent within our shared experience of loss, throughout life.

The first stage is giving the sick person the bad news - that no treatment is possible to control or heal the illness. This news comes as a shock: annihilates the capacity to react or think. Often, at this stage, the person goes into denial; refusing to believe he will die. This period of denial lasts varying time. Sadly, sometimes the reaction of the family doesn’t help. They often will try and kid themselves doctors are capable of curing everything – thus keeping them from the implacable truth. Elisabeth Kubler-Ross describes an angry phase – taking the form of aggression directed by the dying at the doctors, those close to them, those with the best wishes for them. Anger against the sickness itself: anger against death, when it finally becomes manifest and can no longer be denied – its signs now visible in the physical body. An anger which is also directed by the dying person against himself, in the form of guilt. Next is the phase of “negotiation” of trading: where the sick person looks, obstinately, for anything he can trade to halt the progress of the inevitable. Then is a phase of sadness: of swallowing up into yourself – the desire to isolate yourself from all human contact. We can speak of a depressive phase prior to that, of fatalistic resignation in the face of all the evidence. In the best of cases this may evolve to a state of true acceptance: a letting go.

This welcoming of approaching death may be the occasion of a questioning of the sense of one’s life; of the conscious actualisation of death in the body as a real experience, and the awakening to what is really being lost at that moment.

This chronology rarely operates so neatly. What we usually notice is a coming and going between different states. For the accompaniment, this transmigration from one state of consciousness to another state of consciousness is easy to welcome. The carer – be they laic or spiritual – must come to know the different stages if they are to receive them with benevolence and react in harmony with the situation. It is also a very bad idea to react negatively to a person going through one of these often difficult stages which can only be lived at the rhythm of the individual passing through them.

The dying live finitude through their own bodies, their flesh. Those close to them are also present as their loved one progressively degenerates; watching the physical, cognitive and mental changes they play an important role in mirroring those transformations, giving an image of the dying person to herself. A deep fatigue that cannot be healed by sleep establishes itself, progressively, along with weak, slow, movements. The gestures of ordinary life – dinner, toilet – life's ordinary needs, are only accomplished with greater and greater difficulty. The increased difficulty of moving, of trying to work one's way out of an uncomfortable or painful position means the dying person ends up giving way to a total dependence on carers or medical staff. The body clock stops working – the dying person will often sleep all day and wake up at night.

Those surrounding must adapt to these modifications. In the specialised units of the hospital dealing with the dying it is understood the patient should not be woken for care procedures, medical visits or meals. Visitors may come and go freely. A close one may stay all day and all night by the bedside of the dying with the aid and help of the medical team. We often see, at the end of life, stages of anxiety, of agitation, of confusion – sometimes true delirium. Perceptions change. Don't worry about raising your voice, because hearing deteriorates: adapt yourself to the fact the dying person may not see you the same each visit – the eyes are affected as well. Tactile communication is very important – the sense of touch is the sense kept longest. It is important to touch the dying: but only if this is authorised by the dying themselves.

Progressively they breathe more slowly, irregular respiration which pauses, as they rack and, agonisingly fight for breath. They have a pale, terrified complexion. Consciousness changes. Blood pressure drops. The pulse becomes weak, without stable rhythm – finally they are just simply gasping for breath. Total loss of consciousness, the heart stopping, respiration stopping – these are the signals of the final stages.

The Canon of Buddhist texts identify three criteria for death: the loss of consciousness, the loss of heat, the loss of vitality. Vitality is the "vital breath" of ayurvedique medicine. It's an energy which regulates vital processes – and is karmically determined. At the moment of death there will be a dispersion of the five aggregates of appropriation: the five skandhas, and, finally, the flow of successive stages of consciousness will transmigrate according to the laws of causality, becoming available for new births.

It is necessary to emphasise the importance Buddhism gives to the nature of the final thought of the dying. Effectively a last repentant thought, a vow, can influence the accumulated karma of a life otherwise liable to the laws of karmic retribution. This idea can be confusing, at the final phase of life, for Buddhist carers. We can be giving the dying, those experiencing suffering of a particular intensity, sedatives capable of modifying, without examining, particular states of conscience. In circumstances where high doses of morphine are unable to control pain we can, with the permission of the patient, begin what we call sedation of the terminal phase. This sedation, which is accompanied by a total loss of consciousness, is followed right up until the death of the patient: be that in a few hours or a few days. This terminal sedation has nothing to do with euthanasia; it is more like a kind of general anaesthetic which is administered as death approaches. Loss of consciousness comes, eventually, to calm stubborn suffering. However, as we have seen, this can raise complications given the importance of the final conscious thought to Buddhism. As I have said, this sedation can only be given with the consent of the patient, and so, the dying person herself may have the possibility to prepare, spiritually, before a final sleep. One can also ask oneself the question – if the dying person suffers so intensely, how can she

have a peaceful final thought? In these cases, we might feel it justified, in the name of the principle of compassion and humanity, to help put an end to intolerable suffering.

Question. Regarding general anaesthetics, at the end of the operation the patient wakes up again. Is it the case with this sedation?

Response. Generally, there is no coming back to consciousness until the moment of death. I prefer to use the image of a general anaesthetic than that of a coma because we proceed by administering sedatives in a controlled way- monitoring successively how deeply the patient is sedated in order to assure ourselves there is no possibility of suffering caused by too weak a dosage – nor that too powerful a dosage might be bringing about something like euthanasia.

Question. What then causes death?

Response. It's the sickness itself. It's the process of dying itself. This sedation we are talking about is only administered at the end of life when suffering is stubborn and resists ordinary therapeutic treatment. Nevertheless, death can, despite all our precautions, be brought about by the effects of the sedatives themselves; and this aspect of care must be clearly seen and thought through with the help of the patient. Obviously the goal of sedation is not to kill the patient. It's a possibility sedation can cause death: we have to accept this possibility, without, obviously, bringing about death prematurely, by pharmaceutical means. Moreover, certain studies are being conducted to show that sedation, carefully administered, in the final phase of life, will do nothing to shorten its natural course.

Question. I'm going to ask a question which touches on my father who was in intensive care when the doctors decided to stop active treatment. He had, as it happens, a type of sedation of which I am unaware, and he died in one or two days. What I would really like to know is if my father could still hear? And if he would still have been able to speak?

Response. With this type of sedation we seek to erase consciousness because in erasing consciousness we erase too suffering we could not tackle otherwise. In intensive care we generally use all the therapeutic support we can. We can, of course, always look for sedation that appeases suffering whilst trying to maintain a certain clarity of consciousness. The importance, in all of this, is to maintain close contact with the patient. Thusly we urge families to continue to speak, to try and keep making contact, communicating, with their dying loved one. These diverse aims, of lucidity and patient relief can appear contradictory in practice. This is why it is important to fully inform families of what we are trying to do.

When we talk about suffering at the end of life we must be clear about what we are talking about. Of course we are talking about physical pain and a sickness that has become incurable. However, we are also talking about moral suffering, suffering in relationships, in relation to others, social suffering, spiritual suffering. We can talk about a global sense of suffering. The vocation of accompanying the dying is about bringing care to the patient, managing suffering, managing suffering as it impacts on those close to them.

Question. Sorry, but you're talking about "psychic" suffering. What is that?

Response. Yes, I am talking about psychic suffering – but also physical suffering and spiritual suffering – at the end of life.

Question. Yes, but what exactly are you talking about? Are you talking about a kind of psychological suffering?

Response. I am only talking about psychic suffering in the context of the end of a person's life. I am saying nothing about psychopathology.

Question. How often do you have to sedate the dying?

Response. In about 30% of cases. When ordinary care is not working and suffering has become, for the patient, intolerable. We are talking about intense physical pain, progressive asphyxiation, uncontrolled bleeding, extreme anxiety, vomiting you can't stop, severe states of agitation. We only put patients deeply to sleep in a few cases, or for brief periods of time. We have come to realise if we administer lighter doses we can treat patients whilst they themselves can remain in contact with their loved ones. We don't take lightly the decision to sedate. We try and talk it through with both the patients and their loved ones. Sometimes, in periods where the suffering is ameliorated, the carers, those close to the dying, all pose the same question as to the reason for sedation, above all when death seems still a while away. These situations become the object of team discussions because they can in themselves generate renewed suffering, it is therefore necessary to remind ourselves of the intention that underlies therapy alongside our joint objective to support the family. Sometimes it happens that the patient isn't conscious, yet all the evidence points to agonising suffering. The decision to sedate a dying person is taken in consultation after taking into account the wishes, written or otherwise, of the patient as conveyed by a partner, close relative etc – in whom the team has confidence. It's not simply a case of a decision made by one doctor. It's a decision which takes its course and becomes, at a given moment, a sort of testimony for all.

Question. When you sedate someone, can you reverse it?

Response. In certain cases, yes. I'll give you an example – certain of the dying suffer terribly from night anxiety. You can give them something in the night which you can reverse in the morning. Thus ways keeping them awake and lucid during the day. In the case of continued and intolerable suffering we recommend powerful drugs that work without interruption.

Question. When someone is under sedation do we continue to feed?

Response. In that situation we choose to limit therapies that artificially prolong life. The dying person doesn't get any benefit from artificial feeding which, in any way, is usually interrupted. We keep them hydrated, according to their needs, and always continue mouth care with the aim of comfort. Feeding by mouth is stopped when there is the risk of suffocation. This must be carefully explained to the family who may see this as an abandoning of care. We must be attentive to the symbolic force a human being gives to how, the method by which he or she is fed.

Question. Can the family decide in the situation where someone is no longer able to themselves?

Response. To properly take account of that situation we must, each of us here, try and accurately convey what we wish for the end of our lives. That might mean telling a doctor, or someone close, even if they aren't family. The best is if we can write something. This can help

and guide the team caring for us, inform the doctor, and avoid possible interference from others, close to them, that can sometimes contradict the dying person's wishes.

It is important to make clear what we mean by euthanasia and medically assisted suicide because they are controversial subjects right now – tackling them has political and legislative implications.

Medically-assisted suicide requires a doctor to prescribe a drug that the patient, already afflicted with grave illness, administers herself to bring about the onset of death. Euthanasia is when the doctor themselves, after several formal demands on the part of the patient, administers a substance that brings about rapid death.

It's important we know what we are defining in order to understand what doctors are doing – see clearly as we can their intentions and results. Mostly, doctors are dealing with patients who are struggling with immense suffering, who have been ground down to almost nothing by their illness, who have lost any real clear sense of their lives. Sometimes they have lost the sense of their role within their family; within their community, their society. They bear a strong sense of guilt for the burden they seem to be laying on those close to them.

That's where we begin with the work of care and accompaniment: in the framework of the philosophy of palliative care and the necessary ethical dimension implied by our work.

Buddhist ethics, clearly and rigorously applied, can help us understand and help in questions regarding euthanasia and the end of life.

All Buddhist traditions share **three essential points of view**:

- The First Precept states we must not kill.
- We must help people live, as well as they possibly can, their final days.
- Guided by the spirit of compassion and benevolence and, respecting the spirit of the first precept, do the best we can to relieve intense physical suffering alongside all the suffering that is not strictly physical, experienced by the dying.

As a Buddhist carer one cannot simply adopt the position, "I am against euthanasia." Being so rigid would lead us to reject important therapeutic help, to accept death as a natural and ineluctable process, and, in every case, to refuse to hasten the onset of death or precipitate death, in cases of intense suffering. Contrary to this, we should employ all useful, skilful means to control suffering at the end of a person's life. A global approach in respect of the dying person, taking into account the essential value of life and their particular circumstances, allows us to restore a sense, in a time of great vulnerability, of dignity. This is a more and more useful approach: especially living in a society that privileges autonomy, efficiency, speed, gain, power, technical advancement, seduction and eternal youth: while having to simultaneously deal with the facts of a real life really live grounded in the facts of death and sickness, of failure, loss, dependence, the loss of control of body functions, the threat of losing our mental faculties: finally, death itself.

Avoiding equally both an over-reliance on medical and pharmaceutical solutions as much as any possible neglect of care, using all the therapeutic power of care and spiritual accompanying, we can work to actualise the bodhisattva way, as a way of compassionate care.

I want now to talk about Buddhist Values As Realised In The Accompanying of the Dying. Of course we are talking about compassion. There is something about those who are near and those who are close, something about the underlying principle of human solidarity that is experienced as a living Buddhist truth by those giving care and accompanying the sick, at the end of their lives. The perception that others suffer, like ourselves, is at the very root of Buddhism. Compassion for suffering beings is at once an actualisation of a paramita, a supreme virtue, and an opening to awakening. Compassion is not only listening and sharing it is also, when one returns to oneself like this, an engagement with real life, the real situation, coherently perceived as such, as it is.

In Dogen's Shobogenzo there is a short chapter entitled "Shoji," which means life and death: there are other translations, such as, "appearance and disappearance of phenomena," "birth and death." Shoji says, "In the time we call life there is nothing but life, in the time we call death there is nothing other than death." Accompanying and taking care of the dying is to listen to the needs of life itself; to actualise compassion. Rather than saying we are helping at the end of a life why not say we are accompanying the ending of life, life itself, because life itself is just as present in the body and mind of a sick person at the end of life as it is in a young and healthy person. In Shoji Dogen refers to life and death as continuity. If the forms vary, if the phenomena of life is not the phenomena of death, nevertheless, the root of both, the profound root of all phenomena is the same, impermanence, conditioned co-production. We see, in the approach of death, the transmigration of states of consciousness with particular acuity: it's just like zazen, when we watch the flux and change with our own mind. Our own practice teaches us to watch death like this, watch its presence, as wildly fluctuating states of mind and spirit, in the body of the dying, watch these changes with something like familiarity. We can share like this a sort of consciousness of our human vulnerability, the death of another no longer appears as foreign, singular, inaccessible – something we can avoid by our indifference, it is something we, in a sense, intimately experience ourselves. For the bodhisattva compassion begins in zazen.

The second Buddhist idea I want to talk about is that of the unity of body and mind.

Shinjin. A global approach to dying realises its true unity, as a unity of body and mind. At the end of life, when the body begins to fall apart, we often see a disassociation of body and mind. Looking at a broken body in the mirror, a face ravaged by a tumour, can mean the person violently rejects the idea this "body" belongs to them. As carers, we must try and reintegrate this "rejected" body: re establish a new harmony, a "welcoming," a "welcoming back," in the mind of the sufferer.

Question. How?

Response. By the quality of care. By gestures, actions. Care is not a technical thing it's a human thing – it humanises. We can try, for example, massage, touching. These techniques are actually very well advanced in the context of palliative care.

Another value we share is that of the precious value of a human life. We've already talked about this this afternoon and, of course, this morning. In Buddhism a human life is particularly valuable in that it is the only form of sentient life which gives us the opportunity to receive the Dharma and free ourselves from suffering. The first precept is to refrain from taking life. Ahimsa, non-violence to others. This principle has also informed medical care since Hippocrates – "primum non nocere." Firstly, do not harm. Do not harm others, instead, try to help them with their suffering.

In the Shobogenzo chapter: Shoji, Dogen says: "When we understand there is no nirvana beyond life and death there is nothing to reject in life and death, there is no nirvana to hope for beyond life and death." Life and death are what determines liberation: Dogen urges us neither to attach to nor reject death and life. Therapeutic overkill, like euthanasia, are both mistakes: whether asked for by the dying or prescribed by the doctor. These attitudes are condemned by all religions.

In Ayurvedic medicine there is this idea, interesting idea, of a "mature death." You don't die without having exhausted the karma of this life. The chain of causes and conditions characterising the life you have lived is finally given up with the last breath. In this vision, the role of the doctor is to negotiate these obstacles that prevent a person attaining this mature stage of life – without, at the same time, interrupting life, or uselessly prolonging it. In Japan, to designate this medical aim, they use the term i-do: the way of health.

Question. What's the best time to die? "Mature?" What does that mean?"

Response. The best moment is when the last breath leaves us naturally. When our vital energy leaves us. When the five aggregates disperse and the notion of individual consciousness falls apart alongside all ideas of gain and appropriation. When the current that once animated the idea of individual conscience becomes again available for new life. According, of course, to Buddhist faith in the idea of karma retribution as operating beyond death.

Question. Isn't there such thing as an "awakening" just before death. We finally awake just before death. Is this it?

Response. The reality of life and death is independent of awakening. Of course to awaken to the nature of our illusions – it's preferable not to wait for death! But, sometimes, this "awakening" comes with death and influences the unity of body and mind of the being who is reborn. Unhappily, we often observe the final letting go as something suffered rather than embraced by an awakened consciousness.

The value of human life and the ethics of Western philosophical practice unite in the notion of human dignity. I am talking about ontological dignity. The dignity which is ours and shared in the human condition. Briefly, our life is not that of a frog's. There is no equivalence. The particular qualities of human life must be recognised at every stage along its course, particularly at its end. Care imposes a particular discernment and responsibility regarding the decisions each of us make for ourselves and for others. Such conscious choice has karmic consequence. Nevertheless, practically speaking, there is often a tension between the ethical and juridical framework wherein care must take place and the respect of the precepts. A tension which touches upon the work of compassion in lives of prolonged suffering where

those close to the dying are exhausted and spent. The practice of paramitas can be a difficult path for a carer who accepts and lives these tensions. Medical decisions taken at the end of life work within a context whereby the tension between doing good and doing right, the right thing, one's duty, is sometime acute.

We sometimes have to take not the best but the least worst decision. That which causes the least suffering – for the dying, those who care for him, those who help.

The practice of the paramitas, in particular pranja – the right way of seeing things – is, without doubt, useful. It permits us to find, in difficult situations, a way guided by pure intention – a means to use the right means, see, clearly, the consequence of our actions, allow us to take them properly on board.

Caring for those at the end of their lives is also an occasion to practice the “Four Unlimited.” That is to say, benevolence, towards all sentient beings; compassion towards beings that suffer; joyous empathy, equanimity in the face of the difficulties the dying encounter.

Question. I want to say something. I am a nurse who works in a centre for old, dependant, persons. I see all the time actions which are not at all benevolent – from “carers.” I'm there when decisions are taken by doctors unilaterally, which neither the carers nor their families understand. Palliative culture is yet to penetrate hospitals or old folk's homes in any significant way!

Response. Yes. That's borne out by various studies. It's down, basically, to two things. A lack of human resources in respect of a number of services oriented towards the idea of “cure all, and a lack of training for the carers and doctors whose training is essentially technical. The care deficit for people who die at home is even more impressive, which leads, sometimes, to the hidden demands of those proposing euthanasia. A public consultation mission has been confided to Pr Sicard to evaluate the places concerned – without doubt an idea that can be improved upon. The current legal framework – the Kouchner ruling: Léonetti – on the other hand, is very favourable to care of good quality: patients and families should make themselves aware of their rights in respect of these laws, and carers should apply any consequent benefits. It's the reason for which I have decided to devote a part of my work at the hospital to the teaching for training in pain management, palliative care and the ethics of medical practice.

More than 60% of the French die in hospital. Therefore, spiritual accompaniment should, of necessity, take place – with their permission – in public places. The “charter relative to the laity in public health establishments” imposes the strictest neutrality to workers in the health sector – doctors and carers. Laic people accompanying the dying respect, themselves, a charter of practice. Ministers of religion and representatives of cults can be asked for if patients or their families wish.

Question. In other words, no one's there, even ministers, to preach anything?

Response. Ministers or cult representatives only intervene at the demand of patients or carers and mostly to perform ceremonies or rituals. They must respect the individual convictions of other patients. Sometimes they accompany the patients, the families or the medical team.

Question. The approach of death is the time when existential questions arise. Questions with a spiritual dimension. Does this, in your experience, happen often? How do people express this? How do you work with your obligation to neutrality? Do you say “this is really a spiritual question?” Then suggest meeting a priest, a teacher. How do these things happen?

Response. On admission the patient is asked to declare any religious affiliation, alongside any dietary needs. The establishment commits to respecting the beliefs of patients, to giving them every opportunity to practice as well as access to a referent. A list of ministers and referents is, therefore, available in all services. Regarding the question of palliative care, very few carers are trained to identify spiritual suffering and listen to questions of that nature – thus they defer, most often, to a minister or a who accompanies them. If a Buddhist is asked for spiritual accompaniment, or to do a kito – this is very doable, even respecting the wishes and demands of others patients.

Question. There is another aspect, besides a demand made specifically to a cult. Dying can bring about, raise, questions which are spiritual in nature but not recognised as such at that particular time. What do you do? Say this question relates to this or that religious tradition and so put the sufferer in contact with a minister of that particular religion – that kind of “decryptage.” But – that would almost be an orientation artificially imposed on someone by an outsider. Especially if that person is, not in the first place, Christian or Buddhist, etc?

Response. It really is the situation most often encountered, in that the dying person orients themselves towards a particular person of whom he feels will naturally listen to these types of questions. It could be an accompanier, a nurse, a member of the family. Questions may be asked of a member of a cult, if a cult is pertinent. You have to have particular skills in these cases, to spiritually accompany a sick person, and these competences can be acquired and developed. Sometimes a referent of a cult is sought for by a patient and an exchange takes place regarding the essential questions without reference to any particular religion. Certain ministers may find themselves talking to a carer whilst visiting a hospital, they might find themselves discussing openly and freely and possibly, when they encounter a patient in a room, a discussion takes place with the neighbour – a real exchange has taken place – beyond dogmatism. Every situation is different: you may object that this or that is too dependent on one person or another, but my experience has been there is a great suppleness regarding the response to people with spiritual questions. Rare are the demands for Buddhist carers – they mostly come from people of Asian origin, who will be asking for help from the resources of their own proper communities.

Me, I have a tendency to see spiritual questions everywhere!

Question. I was brought along to accompany an ex responsible of the Toulon dojo. When I was there, at the hospital in the North of Marseille, I saw a leaflet posted up, I saw several cults, up there – posted up as leaflets. If people wanted they could contact these people. I talked about it to Armand – he didn’t want to do anything like that. I said to him, “ You know there’s a Buddhist there. A Dr Chevassut. Why not go and see him? “ He didn’t want to do anything and I didn’t push him. Was he really rejecting my suggestion? Maybe what I should have done was have a word with doctor Chevassut – and he would have visited. There you go! It upsets me when I ask myself, “ Was I holding back?” In order not to put pressure on him I held myself

back! Too much! You see what I'm asking myself? But it was there you know, little sign, Dr Chevassut, the Buddhist, right in front of Armand's door!

Response. You know I think its exactly what we do, to respect what you respected. If a sick person is sufficiently of sound mind that he understands he can access certain spiritual resources and he doesn't feel the need to avail himself of these opportunities, don't push him into doing it. Maybe, you know, it was your presence itself that was important then, at that moment.

Question. The question I most often ask myself is "wasn't he, somewhere, in denial of the fact of the next life?"

Response. It's difficult to say just going on what you told me. We can say, very generally, what we expect to see as a great psychological evolution at the end of life is often left incomplete - nothing permits us to force any other conclusion. For example, Kubler-Ross, this psychiatrist who spent her whole life listening to and studying human beings at the end of their lives found herself dying angrily for not having achieved all she wanted in her work. There – its anger we must welcome: for others its denial. To accept is also to accept the impossibility of doing anything else, going any further, and the simple welcoming of this fact can allow us to pass to another state of consciousness – of existence. Psychological or psychiatric intervention is often useful when a state of mind is so stubborn it prevents any possible evolution.

Question. Me, I am work as a witness for the suffering of those dying of asphyxiation. I watched my father die for want of breath – even for all surrounding him it was terrible.

Question. I am always astonished, personally – to die of asphyxiation must be terrible of course – but there are those who drown and are brought back to life. They say drowning wasn't so terrible.

Response. In any case a patient about to die of asphyxiation always wishes it to end. That a solution of whatever nature must be found but, yes, the asphyxiation must stop.

Question. Yes, it's beyond this anxiety.

Response. I don't think it's the same, dying by drowning and dying by asphyxiation. I don't think it's the same.

Question. Because the body can't perform its natural functions.

Response. Yes, when you suffocate you are in contact with the air and this air doesn't get in.

Question. My father is always at home. My mother and I didn't understand because the physiotherapist hadn't wanted to work on the respiratory system. In the end he died at night. My mother found him dead. But I want to ask why the physiotherapist hadn't done his job? We can't understand.

Response. You have to talk about it to him. It's difficult. Maybe he had noticed your father was exhausted, very far gone, and any intervention by himself would have done more harm than good. I guess that was what it was about. When you take care of dying people everything must

be carefully done, every gesture, every action. You have to think, “Will this do good? Will it be bad for the patient?” Will it simply be useless. To take blood a few days before death – does that have any sense? To take a patient for a chest X-Ray – will it add anything, change anything? Everything must be the subject of a collective discussion, maybe that’s what the physio did.

Question. Yes, but in the end, he didn’t say anything to my mother. He said, “No, it’s not worth it!” He didn’t come for the other sessions and, frankly, that’s not good enough for us.

Response. A lack of dialogue and information is always bad.

Regarding the relationship with someone dying at home it is useful to remind ourselves that it is really best to approach someone dying with a spirit of equanimity, peace – a spirit that will influence the patient and establish a serene atmosphere. Keep the lighting soft and avoid loud voices, sobs, vocal crying. Try and keep fresh air and, if possible, light candles and incense. If the person practices Zen, remind them of the Bodhisattva vows. Sing the Hanna Shingyo. You can also ask if they would like to repent. If they would like to wear a rakasu. Maybe put one in their hands all the while reciting the Daisai gedappuku. One can do zazen at his bedside or in his house and dedicate its merits to the person. This underlines that dying is not simply an affair of he who dies: it is also a community thing, a social thing, it encourages solidarity, humanity and reveals to us the interdependence of all sentient beings.

Question. Have you heard about those who’ve come back from death who describe experiences outside the body? The shining tunnel? The feeling of unconditional love? Have you had any experience of people coming back from the dead?

Response. You’re talking about those who’ve come back from the dead. I haven’t really seen it but you hear about it. An antitheist and a neurosurgeon, both interested in the subject, have written a book collecting descriptions, by the people themselves, of what happened to them. Some of their conclusions, personally, I don’t find convincing. Nonetheless, many things that have happened – it’s difficult to explain them rationally. The authors believe they have collected a sufficient amount of evidence to suggest a life after death. If that reassures people, helps them, then why not? For me the idea of life after death is not something to be scientifically proved but is rather an act of faith that defies logic. Bodhisattvas have enough to do in this life we are living right now.

Question. Some people have been transformed after being cured of cancer – just like the experiences you are talking about. What do you think of that?

Response. It happens often that, after extreme, tragic experience people are not the same as they were before. They have found certain serenity, certain benevolence towards others, they had not known before. Maybe it’s a form of awakening to the urgency of the present moment, a waking up to the essential in life.

If there’s enough time left we can talk a little about the “clinical vignette” which is not, strictly speaking, part of a spiritual accompaniment responding to a patient’ demand, but rather something else. I am talking from the standpoint of a medical approach but Nelly will come at it from a different angle, giving another report on the accompaniment carried out by voluntary workers.

I met this patient in the palliative care unit after a morning visit. A visit to the palliative care unit is not like the hospital visit you might imagine. There's a formal aspect to the visit that is not always the most important thing. After the visit the doctors, the carers, other interested parties all take on various questions while chatting with the patients. It's often during these times, when everyone is together, the most important decisions are in fact taken.

Nelly is 60 years old. She is married with two girls of 25 and 30 respectively. She has had recurring breast cancer with multiple metastases particularly in the lungs where she fights for breath and needs an oxygen mask to breathe. It is not, in her case, a question of uselessly prolonging life but ameliorating suffering, giving her a better quality of life. She also has metastases in the bones and the spine which has brought about a compression of the marrow and a paralysis in her legs with crippling pain. The pain itself has been well treated. It is her respiratory problems that really hit me when we meet. It's her fear of dying of asphyxiation. We usually talk about, in such cases, fast deep sedation that can be administered to the patient, as soon as she asks, when she herself finds the situation intolerable. Telling her this reassured her. She has already been informed – but she needs to be, as is often the case, reminded of this recourse, offered some kind of reassurance.

The second question she asked me is if she will be able to walk again one day. I had to explain to her there were treatments being administered to control her back pain, but in no way would she be able to walk again. It was a subject I had already taken up with other carers, and here she was “negotiating” with a prospect that was for her unacceptable. The perspective for her was of staying in bed until she died. What impressed me was that, while doing this, she was putting together these very long sentences and ending up totally out of breath, exhausted. I suggested making shorter sentence and breathing in between. It was like this that I was able to offer her an opportunity, which had arise through suffering, to introduce another dimension to the exchange: I suggested she concentrate her breath, observe how this felt, then deepen it. She was experiencing her body as dead from the waist down: I said observe this too, let go of all thoughts about it. I was sitting opposite her “being” the rhythm of her respiration, till I noticed it slow down. After a few minutes I asked what she was feeling. She had noticed she was breathing more calmly and was feeling more peaceful inside. I said to her, “your physio isn't working like this but, what I am suggesting to you, proposing, is something like a harmonisation of body and mind.”

I explained to her that she could always go back to this technique when she needed to. I said to her that her system of administering oxygen was not working but, nonetheless, she was now clearly more comfortable, much less anxious and she could maybe give it up.

It's important to underline the importance for doctors, carers and citizens to each know their respective rights and obligations concerning good practice in respect of care of the dying, be that be in the home, in care centres, or hospitals, with the aim of reducing assisted suicide or requests for euthanasia.

To finish: the last words of Dogen's *Shoji*.

“There's a very simple way to become Buddha.
Don't do bad
Don't attach to life and death
Prove yourself capable of profound compassion

Towards all living beings
Look up to more experienced practitioners of the Way
Cast a benevolent eye on the less advanced.
Be free of the spirit that attaches to the numberless things
Be free of the spirit that wants to possess them.
Don't tie yourself to regret or sorrow
That's what we mean by the state of Buddha.