
Proposals for accompanying people who are ill

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Abstract : Zen Monk and volunteer accompanying people who are ill and nearing the end of life, Pascal wonders how he can provide a spiritual accompaniment to the people who are dying. « Spiritual suffering calls for a spiritual accompaniment », he says. He shares with us, through a detailed article, some observations he made by the critically ill, and tries to answer two questions :

- How can we link the practice of the Way and the accompaniment?
- What could be a spiritual accompaniment for people who are living the last moments of their lives?

He concludes by saying : “Accompaniment is an authentic spiritual way. It is the continuation and the actualization of my practice of zazen. It allows me and the other person to experience the awareness of being connected. And the joy of feeling alive.”

I'm going to present to you as clearly as possible what I do as a volunteer accompanying people who are ill and nearing the end of life, and my commitment to the Zen Way. Share some of my concerns with you and also parallels we can draw between accompaniment and the practice of the Way.

I am a volunteer accompanying people who are ill, seriously ill, and for some, nearing the end of life. The term « volunteer » is important to me. The word for volunteer in French is « bénévolé » which is close to the word benevolence, which means wishing good for others without imposing anything. Impose nothing, this is one of the attitudes to respect when accompanying others, and this reminds us of « just being » in zazen.

I am a volunteer for an association which is part of what we call palliative care culture. The most important part of this palliative care culture is palliative care itself, but not only. We can formulate what this palliative care culture is in this way :

« When we can no longer influence the course of an incurable illness, the person who is ill continues nonetheless to remain a living being who presents symptoms which are a source of suffering. The treatment for this suffering is palliative, in that it doesn't treat the illness, but the person who is ill. It doesn't claim to cure, but to give relief. »

Professor René Schaerer

Palliative care and accompaniment consider the person who is ill as a living being and their death as a normal process. They neither speed up or delay the process. Their goal is to preserve the best possible quality of life for the person who is ill.

I have been a volunteer in hospitals and for some time within an Ehpad (Care Home for dependent elderly people)

Two questions that we are going to develop now :

1. What link can we make between the practice of the Way and accompaniment?
2. What could be a spiritual accompaniment for people who are living the last moments of their lives?

Understand « spiritual » in its deepest sense. In other words including all the aspects of a person, physical aspects, psychological aspects, social and existential aspects and of course spiritual aspects.

We should also be aware of the difference that we need to make between what is religious, what is religion and what is spiritual.

Religious questioning only concerns believers belonging to a religion. Whilst spiritual questioning concerns every human being, whether he is conscious of it or not. The spiritual dimension is inherent in human beings. It touches what is deepest within all of us, our essence, our true nature as Buddhists say, and not only our daily existence with its specific characteristics.

The spiritual in accompaniment has nothing to do with any kind of intellectual knowledge, but rather the experience of meeting another. It has nothing to do with any kind of belief, but rather a feeling of trust between two people who are accompanying each other for a part of a journey.. For the person who is ill, the spiritual dimension is felt within the need and the necessity to feel connected. Vertically connected with himself. Horizontally connected with others : the family, the nursing staff, the volunteers, the community etc;

The spiritual dimension is therefore above all to do with meeting and making a connection. Understand also by « spiritual » the possibility of exchanging ideas and of sharing that exists between two people, between the person who is ill and the volunteer. Then, in such an exchange, perhaps the opportunity will arise for each person to work with what is essential. We can then say that the two people accompany each other.

« Initially the real request of the person who is ill and nearing the end of life is to be taken care of so that they are not in pain or discomfort. This is the most important thing. When things are in place and the ill person's comfort is assured, this change can occur, this way of progressively moving towards another dimension of being.

This is not expressed. It's not always formulated in words, but it's to do with acceptance and transformation.

Because of the atmosphere, the respect within the department between the nursing staff, the volunteers and the person who is ill, such a change is possible. »

Doctor Salamagne

Spiritual dimension. Physical dimension. Psychological dimension. Social dimension. Existential, religious dimension.

The accompaniment volunteer and death

Before going any further it seems essential to me to say that an accompaniment volunteer, and moreover an accompaniment volunteer following the Zen Way, must be convinced that death is not an end, or in any case, not a failure.

Not a failure in the sense that occupies us now. Let's not consider the deaths from war or assassination which are a true failure for humanity, as Maurice Zundel (Dominican, writer and poet) said.

The approach of death can lead to terrible suffering, but also sometimes great moments of opening up. It can go one way or the other : from complete devastation to wanting to be totally part of the world before disappearing.

Death is part of life, it's an event to be experienced, a reality and maybe even the great reality which can awaken us. I like to say that it can be the real and only moment of rebirth. The moment to truly abandon the ego.

It's perhaps the occasion to give the last gift to those who remain. You give your life again, you don't lose it.

In any case, as Elisabeth Kübler Ross, a pioneer in palliative care in the US, said, death, the approach of death should be considered as an important stage in life, as the last stage of growth of a man.

We shouldn't mess it up

That's why it's important to have a genuine accompaniment.

Parallels between the Zen Way and Accompaniment

I would like to make a first parallel which, for the accompaniment volunteer and practitioner of the Way that I am, seems quite important, in any case, important enough to give me some help.

It concerns the experience that Shakyamuni made 2500 years ago and that radically changed the rest of his life, namely the 4 meetings with:

- the sick person and illness
- the old person and old age
- the corpse and death
- the monk with his shaved head and wisdom

Illness, old age and death, each of us, like the Buddha, whether we be accompaniment volunteer or carer, experience them all the time during our activities. The fourth meeting with the monk with his shaved head, happens through all the contacts we have with the nursing staff, the other volunteers (and also with the families). All the nursing staff and volunteers are

true Bodhisattvas at the bedside of the ill. The accompaniment practised at this time is the true work of a friend.

Benevolent friend and, perhaps, for certain, sometimes spiritual friend.

From this, I would like to make a second parallel. Build, if I may say, the four noble truths of accompaniment.

- First Noble Truth : The end of life is suffering. Physical suffering, psychological suffering and spiritual suffering. Within psychological suffering we can also place social suffering, family suffering and the existential suffering related to religion.
- Second Noble Truth : The causes of this suffering are quite obvious : illness and all the deterioration linked to old age, dependence, accidents, isolation in all its forms (family, social, mental and others.)
- Third Noble Truth : Fortunately nowadays we are able to lessen this suffering in a great majority of cases. Medical progress, the commitment of carers and accompaniment volunteers in palliative care, are proof of this.
- Fourth Noble Truth : For that you need to follow a way and truly develop it. That way is the way of palliative care and accompaniment of people who are ill.

I think this way of seeing things is important. Important and energizing in that it will connect accompaniment volunteers, who also follow a practice of the way, to a tradition which will give them strength, support them and clarify things for them.

The harmonious combination of a path of awakening and accompaniment will mean the volunteer is more inclined toward a belief in the positive transformation of a human being.

A human being evolves right up to the end.

With this in mind we recognize the other person, the person who is ill, as similar to ourselves, as our reflection. The person who is ill becomes part of our lives for a time, it's important to us to be completely together on this particular path - that of the end of life.

Accompaniment and treatment of suffering

The physical and psychological suffering are treated with great efficiency by the care providers – doctors, nurses, auxiliary nurses, physiotherapists, psychologists, social workers etc.

This personnel ensure that the ill have dignity, quality of life and, for some, a certain autonomy. Everything is done to lessen as much as is possible the physical pain and, through this, moral suffering, thus allowing the ill person to keep the best possible image of themselves. But when existential suffering, and sometimes spiritual suffering, come up to the surface of consciousness – in my opinion they can only be treated by the accompaniment volunteers. Of course within a palliative care team, be it the carers or the volunteers, nobody would claim to be a specialist of these questions. Especially as each person will be responsible, at one moment or another, within their own field of competence, for the existential and spiritual suffering of an ill person.

The only difference is that the accompaniment volunteers, unlike the carers, do not have a therapeutic imperative, do not have a therapeutic project, and can therefore offer the necessary time to the ill person. So here there is a notion of time which comes in. The time of the care staff is not the time of the volunteers, which is not the time of the families or that of the ill person etc.

This notion of time, is the time of a gradual process.

What ill people need most is to be received in this time which is theirs. To be recognized there, as they are, where they are, and to be accompanied step by step.

This requires above all humility, an open mind, a capacity to hear silences and an acceptance of what is beyond us.

To do nothing more than be there.

Before we considered three types of suffering : physical suffering, psychological suffering and spiritual suffering. This means that they belong to three constitutive elements, or three bodies namely :

- that physical suffering is related to the physical body
- that psychological suffering is related to the psychological body, to the ordinary mind , the thinking mind
- that spiritual suffering is related to something more essential in us to do with consciousness which we could call the spiritual body

Ideally these three bodies should be interdependent and function in perfect harmony.

Unfortunately it's not the case most of the time and it's maybe because of this that a certain dissatisfaction pushes us to practise a way of awakening. To awaken this three dimensional being that is lying dormant deep within us.

Normally a certain harmony exists between the first two bodies. We often say body and mind in unity, it's of that order. But the spiritual body is often unrecognized or even totally ignored.

However it is there, it's not absent.

Moreover in certain end of life experiences, it's presence is confirmed : we have the impression that the spiritual body is trying to come up to the surface. That must come from the fact that the physical body and the psychological body are greatly diminished, without defenses, so an opening, a passage is created to let it emerge perhaps. In these phases ill people discover new possibilities, questioning that they had never had before, regrets of not having experienced what is essential.

That can be the opportunity to go one step further.

Or that can be another suffering added to the first two.

So, how does this take place?

Or, how can you accompany someone who isn't necessarily asking to be accompanied?

By way of introduction these words from Professor René Schaerer (main founder of the Jalmaalv association).

«Sometimes, at the bedside of a person who is physically or mentally in a very bad condition, I imagine that this person was once a child, a young man or a young woman full of life. In love for example, father or mother. I find this gives another perspective and another meaning to what we do. Just as the person has several dimensions in time, he or she also has several dimensions within the moment they are living. I deeply believe that we exist through the links that we have with others. It's this connection that we try to bring to life in palliative care and accompaniment, not to make it survive, but to bring it to life»

What is said here is the reality of our total interdependence with each other and the necessity of restoring a link, the essential element in any accompaniment.

The link - this means connecting again, connecting with each other, it's like a bridge between two people. The link is also the relationship, and it's perhaps more than this - a meeting. A relationship would be more in the social domain, whereas a meeting would be more in an intimate domain, of depth and why not, of spirituality.

We need therefore to tend towards a meeting.

How can we foster this meeting?

Before anything else, we need to remember that an accompaniment volunteer is not part of the nursing staff, even if he has an important role to play in the health system. What we need to understand by this, is that he has no therapeutic project, no therapeutic relationship aiming at any sort of objective, and it's better this way.

Moreover he has no project at all, except that of meeting the person who is ill, restoring a link and restoring meaning.

So how can this meeting be fostered, hoping for a two-way meeting, in other words a meeting between two human beings who are going to try to live something together. A meeting like a part of a journey that we will do together, either peacefully or not. Like a window that we open on two people who are going to recognize each other in what they have in common, in other words the same condition of being a human with the same thirst for meaning and connection.

Perhaps Jacques Lacan gives us a solution :

«Each time that a man meets, speaks to another man in an authentic and complete way, something happens that changes the nature of the two beings present and brings them closer in an even deeper meeting.»

An authentic and complete way, this is the key that we need.

But what is an authentic and complete way? It's complete presence in the moment, totally here and now.

So the meeting, if it's going to happen, will come into being thanks to complete presence, through the ability to be completely present towards the person who is ill. Because of this,

presence is fundamental to all accompaniment – be it that of the nursing staff or the volunteers. We could even say, in some circumstances, that presence is in itself a spiritual act.

Presence

As an accompaniment volunteer, I attach a great importance to this notion of presence. Of course, not any sort of presence. It's not a question of occupying space, of keeping the ill person company as we would during a simple visit. It's not something superficial.

The presence that we're talking about here is a way of being during the accompaniment. It's, if possible, to really reach the mystery of the person. The presence that is then offered to the ill person is beyond the conventional because it is strengthened by the compassion that we give to him. Compassion which I think should be understood as a means of creating a space where things are possible for the person who is ill.

« Everything is still possible for you and I am completely by your side. »

We need to understand, and it's in some ways obvious, that accompaniment can only be experienced in the present moment, here and now, at the bedside of the ill person. The person who is ill experiences the illness in the present, endures it in the present. It's therefore an obligation for the volunteer, towards the person who is ill, to be present to that present moment. And it's in this specific and almost intimate presence, that a certain authenticity comes into being.

These moments of presence are moments where the ill person is recognized in his or her totality. He is recognized for what he is, a human being and not a pathology, a case, a broken body, or even worse a simple number in a file. To offer this presence is to meet with an equal. It's to meet a person who is infinitely more than what they are through the illness. This reassures them, makes them feel safe. It's what I called earlier « creating a space where things are possible. »

Furthermore, presence is to do with receptivity. Having a mind that is receptive, free of all preoccupations and especially free of judgement. This receptivity of the mind also creates a great receptivity as to what can or cannot be said. In a way it's what we call « right attention » in Zen. Not creating a screen between the volunteer and the ill person.

This presence should be stable and full of energy. This is important for the ill person who can use it as a way of remaining grounded. It's also important for the family who, if they want, can lean on someone who is present, reassuring and there to listen.

« Men cannot be saved by speeches, but only by a presence, and this presence can only normally appear to them through a human face. Be the window through which the sun sings. »

Short text by Maurice Zundel , accompaniment volunteer, Dominican and writer.

Listening

Completely present, knock on the door of the bedroom, open it, enter and sit down next to the ill person. Don't expect anything in particular but just remain fully present. Understand, and let

the other person understand, that there is time and space to receive what can or cannot be said. In other words – listen.

For this we can use active listening techniques and reformulating. Learning to ask the right questions at the right time. Knowing when to speak and when to listen. Being able to listen to the concerns, apprehension and fears of the person who is ill, without judging anything. Being also able to listen to our own concerns, apprehension and fears – and not judging them either. Making sure that they don't stick. Understanding their impermanence and thus not projecting them onto the person we are accompanying.

But if we want to go further with accompaniment and let the ill person's and the volunteer's spiritual dimension appear, we need to rely on a much more intuitive listening. Listening which is « I shin den shin » as we would say in Zen. In other words remaining attentive to a word or the word which is the gateway to go beyond.

To listen in accompaniment is therefore not always to speak. It's often, even very often, listening to silences. Silences in which something is said and which sometimes escapes us. Paradoxically the fact of accepting, of letting go, reinforces our accompaniment. When we abandon everything, we can receive everything – it's of that order.

Listening thus becomes a truly spiritual exercise. An exercise which involves both the ill person and the volunteer. Both, when it's meant to occur, progress along the path. Sometimes a strange path. This path is that of life, and life is fundamentally spiritual;

«In the sacred song of silence, listening and the words that follow, like silver droplets, take on a strangely calm amplitude».

Doctor Daniel Chevassut

Confidence

Entering into the ill person's room is always a first time experience, even if we have done it before. This is why confidence is absolutely necessary. It's the backbone of all accompaniment. Confidence reinforces the presence and the capacity to listen because it brings stability and groundedness into the relation with the ill person. We need to understand that this confidence must be two-way : the ill person must have confidence in the volunteer, the volunteer in the ill person.

The ill person must have confidence in the volunteer because confidence will bring him the security, the protection and the recognition he needs. Once it is in place, it is soothing, calming and even sometimes healing for him. In any case the ill person has a deep sense of being understood, listened to, recognized, connected. He can then open up much more easily and if he wants, reveal a more intimate side of himself. It's through having confidence in someone else that we gain access to a certain dimension within ourselves.

The volunteer must have confidence in the ill person in the sense that the volunteer must have confidence in the ill person's inner forces. Have confidence in his potential to see things in a new light and so integrate the spiritual dimension, in other words, the profoundly human dimension of his accompaniment. Understand that even if the illness progresses and that death is close at hand, an inner work always takes place. If we are conscious of it or not, it happens.

For some ill people it will be the opportunity to be born again, to be reborn. For other ill people this doesn't happen, but it happens to the volunteer who is accompanying them. The volunteer should have confidence in what can emerge from his accompaniment, for the ill person and also for himself : « open to all the dimensions of human nature, even those he is unaware of », Jean-Yves Leloup

Presence, listening and confidence lead naturally to a meeting between two people. This meeting is to do with re-connecting, re-uniting, restoring a link, connecting two human beings. This meeting can only take place within the present moment, it relies on presence to what is happening. That is when it will allow what is deeply felt and which can no longer wait, to come up to the surface. Meeting another also allows you to give, to give something of yourself. Let's remind ourselves of these words : « Life is not lost, it is given again. »

But for this to happen, meeting is necessary.

«Every human being needs to meet another to be fulfilled.»

Maurice Zundel

The space of meeting

What is experienced in this space? The important questions come up and with them the great fears and losses. The end of life reveals our fears, our fears of the unknown, and consequently our uncertainties and our need to give meaning to all this. As a person in good health, we block out these fears most of the time. But as an ill person, and for some people who are close to death, these fears come back insistently, as if to obtain an answer.

Accompaniment gives ill people the opportunity to welcome all these fears, to recognize them as being without substance, or at least, able to be managed with a certain efficiency and avoided when they turn into anxiety. It's easier to deal with the fears, to understand and to defuse them than to get out of the labyrinth of anxieties which are often all-consuming.

The main fears which come up are :

- The fear of suffering
- The fear of being dependent , of losing autonomy
- The fear of being a burden for the family
- The fear of separation, solitude, of breaking links (with the family, friends, society etc...)
- The fear of being abandoned, forgotten
- The fear of bodily deterioration
- The fear of psychological deterioration (Alzheimer's)
- The fear of an uncertain future
- The fear of losing, of being lost

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- The fear of exclusion

There are of course many other fears, the list is not exhaustive. Fear of death comes afterwards, you could nearly say, in last place. But with it come questions of another kind, those which touch on what is the essence of being. For example :

- Everything is falling apart, does my life have meaning now?
- I'm afraid to lose this life
- What is death – does it have a meaning?
- Is there something after death?
- How can I live these last moments?
- What do we come to do on Earth?

Once again this list of questions is not exhaustive. There are in fact as many questions as people to accompany. Moreover, not all the ill people that we meet necessarily want to question themselves about the meaning of existence and of their death. Some ill people pass away ignorant of, or perhaps wishing to ignore all these questions. It's not an obligation to have them. As a volunteer we also need to accept this.

Wishing to give meaning to our lives in the last moments is not easy. Very often this calls many things into question, about one's past in particular. But when we are well accompanied, it's the opportunity for a real self re-examination. Maybe even the perspective of another life, even if it's very short. It's also the opportunity to understand that loss is the essential experience of life, it's the experience of impermanence and acceptance. We will come back to this a little later on.

In any case, this can be the moment of a true re-evaluation. I mean by this the possibility of going back to a place in our past which will permit forgiveness, asking for forgiveness, declaring love, giving etc. I also call this the place of « fuse » this special gift which is given unreservedly and which can save both the person who is dying and their family. It's a question of making the person who is nearing the end of his life understand that he can forgive, ask for forgiveness, even if the person he is addressing is not there, or has already died. The important thing for the dying person, in this case, is to feel reconciled. Maybe he can still express all the love that he has for someone, etc. It's, once again, a question of connection. Connecting, forgiving and loving. And then the end of life can be redeeming, as Marie de Hennezel so nicely puts it.

On the other hand, sometimes during our accompaniments, we observe a sort of fight. A fight which is certainly between the me which does not accept the end of life, we could say that it does not accept the end of its life, and something else, which is deeper and accepts it totally. It's a struggle between the thinking mind which fights and the body which knows. This fight is necessary at a certain point of the illness so that the ill person can react and be an aid to all the means put into place to treat him. But afterwards he mustn't stay locked in this fight, it exhausts him more than it helps him. Of course everything should be used to continue to bring him relief. The end of life is not a war against death. The accompaniment volunteer should,

with the help of the ill person, lessen the hold of this fighting process. Simply through recognizing the ill person as a living person in his own right. Telling him that it's not because death is close that there's nothing left to live.

So the time that is left to him is of great value. It's a time of acceptance, of letting go, or rather of letting things be. It can be a liberation.

Acceptance

Acceptance is one of the stages that the dying person experiences, according to Elisabeth Kübler-Ross (American psychiatrist and pioneer in palliative care.) It is the fifth stage. It comes :

- after denial : no not me, I'm not ill, I'm not going to die
- after anger : why is this happening to me?
- after negotiation : I must buy more time
- after depression : which is a sort of mourning period before one's own death

For Elisabeth Kübler Ross acceptance is the moment when things are in order ; the situation is as it is, and it's good that it's this way. For all that - acceptance is not resignation. It's not of that order. Accepting one's state as a person nearing death, accepting one's fears, the disintegration of the me and of one's image, is not resignation. Acceptance is, in the final analysis, saying yes, yes to life and yes to death. Accepting death is agreeing to disappear. It's preparing oneself for this and preparing oneself to give one's life again. Acceptance is quite simply approving of things as they are. So it's being capable of receiving one's death, of welcoming it, a little like Cyrano, but not necessarily with a sword in one's hand. On a spiritual level, it's maybe beginning to see that behind this death, the way continues. The way is always there, generously offered to us. Death can then become something more than a simple and final end. It's the moment to give one's life again.

And as a certain philosopher (whose name I have forgotten) said :

« Accepting one's death, is taking the decision not to die, because ultimately there is no death, there is only life. »

Letting go

Letting go, is letting go of everything mentioned earlier. It's making the ill person understand that he is much more than his state as a person nearing death. That he is much more, infinitely more. So then maybe he will dare to face the unknown and let himself be carried by something that's greater than himself.

Acceptance and letting go are eminently spiritual, they are the first steps and also the last ones which lead towards a certain liberation.

Towards a certain liberation

Liberation from what? Certainly, in the end, liberation from attachment to the ego. But for this to really happen, you have to have developed, in my opinion, a certain awareness of the reality of what is, through the practice of a spiritual path.

For all that, without speaking of a spiritual path, it is good to lead the ill person towards a liberation from certain mental processes. If these mental processes are not clarified, understood and transformed, they will keep him locked in what we earlier called a fight. A fight between the me, in other words the ego which refuses the reality which is being experienced, and the body as well as the deep Self which accept the reality. I mean by « deep self » the spiritual nature of all people, their true nature.

These mental processes are as follows:

- **Doubt** : it calls into question the value of existence and leads to resignation « What's the point? » « I am done for... » Doubt takes confidence away and isolates the person. The ill person doesn't want to hear anything any more. He closes up. What the volunteer can do when faced with doubt is to remain present and confident. To be, in a way, the antidote to doubt. Saying to the ill person « you have the right to doubt, but you can also adhere to something else. »
- **Despair** : it's to feel totally abandoned. The ill person despairs of himself, of his forces « I won't make it.... » He feels lost. He is no longer connected. Faced with despair the volunteer must try to restore a connection. Make the ill person feel that he is not abandoned and perhaps if it's possible say : « it's when there is no more hope that hope in something greater than you is born. »
- **Anger** : it's the expression of the revolt of the me. There is panic and also impatience. Impatience towards the carers, the volunteers, the family and ultimately oneself. Faced with anger, the volunteer mustn't feel ill at ease, it's not directed towards him. He must remain the witness of what is happening and be patient. Breathe calmly.

By way of conclusion

All the work of the accompaniment volunteer will be to remain confident in the face of doubt and despair, will be to remain patient when faced with anger. The presence of the volunteer will help the ill person to remain grounded so that he may live what he has to live.

So when we hear an ill person say « things are in order for me now » or « thank you for supporting me », our work as a volunteer is rewarded and more than this. Nothing was useless. For us too, things are in order.

Despite everything, all the ends of life are not peaceful, serene, natural etc. Revolt, anger, anxiety are, in many cases, always present right up to the end.

The volunteer has to accept these tragic moments. It's difficult but that's how it is. He finds himself faced with something which escapes him, ungraspable, unknowable.

For all that, as far as I'm concerned, accompaniment is an authentic spiritual way. It is the continuation and the actualization of my practice of zazen. It allows me and the other person to experience the awareness of being connected. And the joy of feeling alive.