
Caring for children suffering from incurable diseases

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Abstract : Heike works in the field of accompaniment to children with incurable diseases and providing support to their family. "Reflecting on your own experiences of loss and grief is not only a prerequisite for anyone who wants to accompany, but also a wealth of experience in which we can draw ", she said. She illustrates her practice with many examples of actual and practical experiences depicting her daily life and requests she was requested. Even if she has no solution immediately, dialogue and active listening are used to define with the families the best support. The most important function of a personal psychological health is to think constantly about who we are and what relationship we have with ourselves. "What is my position in life in the confrontation with suffering, dying, death and bereavement?" "What kind of support do I need myself, to be able to accompany others on their life path? »

What led me to such a path?

When I was 28, I was pregnant with my first son. I was happy but my father had caught cancer. My son Simon was born on a Friday and the following Sunday around noon I went to lie down to rest, I was very relaxed but when I woke up I was told my father had died and that he was in the same hospital two floors above. He had waited for the birth of my son in order to die.

It was my first conscious encounter with the reality of birth and death, joy and mourning. Later my mother fell ill with cancer and I took care of her during 9 months. We had asked for help to a hospice care unit. I wanted to help her the best I could and the women of the team gave me a lot of strength and energy. They told me how I could help her; how I could prepare my children, talk to my husband.

At that period I met Roland and zazen. I was doing my first sesshin in Grube Louise in May. So I carried on doing zazen, and I came across the service of palliative care. Then my mother died on the day of my second son's seventh birthday.

Then I spent two years mourning because in fact I had started mourning my father after my mother died. At that period, a lady called me from the German children's association for palliative care and asked me to join the ambulant service. And since just before that, I had decided to take a new professional orientation, this call came right in time and I started to work in that field.

I'm going to talk about my experience and also its relation to the practice of zazen.

Some experiences with children's care and assistance to their families

The main axis of my experience is the work at the end of life children's center.

I am going to address 3 aspects:

1. The spiritual aspect

In German the word “spiritual” is used since the 60’s. I refer to Ida Lamp’s definition in the context of hospital care: spirituality is “the quest of the human being to find existential meaning to his life, suffering and death... the sources and the aim of existence.”

2. The structural aspect

The work of the children’s end of life unit has a well-defined set up, a structure that offers training and is composed of volunteers. The structure offers support and means so that there is mutual aid and cooperation in the team.

3. The supporting aspect

How can support be practically given within the work at the children’s center?

One’s family in life

As I experienced it, I was pregnant and my father was dying. Life and death were very close. If I consider the usual model of the families I assist; a family expecting a child, looking forward to the perspective of a happy and healthy family life, then they find out about the diagnosis: the child has an incurable disease that will shorten his life and he will die during childhood or youth.

The following stages are typical of what these families go through: the diagnosis – life – loss of capacities – mourning (of the healthy child) – dying – death – mourning.

As a bodhisattva and a former coordinator of the children’s ambulant service, I took care of more than 30 families.

- Families who asked for support just after the diagnosis
- Families who asked for support some years after having received the diagnosis of their child’s incurable illness and who have been facing this situation for some time
- Families whose child has cancer, is going to die in the weeks or months to come
- Families who have already lost a child with cancer and who need to stay in touch with the center to share their experience and even take part in the small parties we organise.

My main duty was to give time for talking and listening.

Even if I came across distressing life situations, in different circumstances, they all have similar needs. If I talk about it, it is also to emphasize that each one of us can take part in such care.

- By being present with compassion, by listening, answering questions and bringing support where it is needed.
- By meeting the family with respect and acceptance, without condition.

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- By creating a regular and reliable contact based on listening and compassionate and sincere care.
 - But above all support is affection and regard

Christine Longaker, a Tibetan Buddhist disciple who has 20 years of experience in a unit of hospice care, said:

“More than anything we may do or say, it is the way we are that helps a suffering person. The way we are is our position in life with all our experiences, good and bad.”

In a mondo, Roland Y. Rech said concerning compassion:

“Contemplation during zazen makes us become intimate with these processes. We perceive very clearly the way we function. During an encounter with someone we can quickly find out what is happening within us, and think: “That’s me”. We keep an open mind to understand the other as he is.”

And I add that we have to listen and grasp what the other person wants, trying to understand what he really wants.

Care and support within the framework of children’s care

It is the family who decides the way they want to be helped and the kind of assistance they need.

These needs vary. Children and young patients want someone to play with, mend things, cook, read, but they also like to ask important questions they have not had the chance to ask yet about dying and death.

Patients wish to talk.

Brothers and sisters also like to have visitors, do something nice or be allowed to ask questions they never dared asking.

It is the duty of the caregiver and the family to express the needs together.

- The needs of the family have to be discussed to be identified
- When the needs are clearly expressed, the way to provide assistance has to be thought over
- Because competences and experiences are different, each one at his level is invited to express himself and act. I say that because everyone is capable of doing it, not only the professionals.

Becoming active, yes, but how?

The conditions of intervention are situated at the meeting point between the need of the family, and what the caregiver can offer.

From what has been decided, the needs are identified, the means are defined. It is in fact the start of the caregiver's responsibility. That means for each caregiver to accept the family's needs as the measures, the instructions for his own actions. It is a duty of service that is determined by the aims and the path of those he or she is assisting.

Furthermore it is important for each caregiver to realise the limits of his intervention and his field of action.

Practical limits

When the needs of the family lead the caregiver beyond his limits, he or she has to express them and other solutions should be looked into: who or what could help the family with such needs. It is for example possible to benefit from further support from networks the family is involved in, according to location there are:

- Ambulant services for children
- End of life units for children at the hospital
- Palliative health centres for children
- Ambulant assistance services
- Support services to families
- Offers of spiritual and religious support
- Groups of mutual aid for a particular illness
- Offers of specific leisure activities
- Networks for family members of deceased children

Personal limits: who am I?

Good will and motivation draw in the involvement of a person's time made available to those who ask for help. When taking care of children, I came across people driven by very different motives. Here are a few examples of motives to get involved as a volunteer:

A woman said: "My children are grown ups now. I've had so much joy with my family that I want to share it with others."

Or another: "I have myself been in a difficult situation with my child and I know how important it is to get support. I know what was missing for me and I want to be there for others."

One volunteer told me he was motivated to become a caregiver also for himself. It gave him the opportunity to learn a lot and address his own mortality either in training or with the people he met.

Personal limits can be intensified during situations of personal crisis. During such a situation we can be so absorbed in our own problems, we eventually lack the sufficient distance to help others.

It can be the case during mourning, profound experiences of loss that are not yet totally accepted or overcome, and so allows no place and availability to give care.

When giving care and support, it is important to situate oneself and ask the following question: "How would I react if I found out I had an incurable illness?" We find out we are going to die 6 months later, what life position are we going to take? What anxieties and hopes arise and what do we do with them? To personally confront the perspective of dying, death and mourning makes us stronger. To think over ones experiences, loss and mourning, is not only a preliminary condition for someone who wants to become a caregiver, it is also a wealth of experience that can be drawn from. With my personal story I had this wealth of experience. I assisted many families.

Each one should know his limits and to what extent giving care is possible. He or she should be aware of his conception of death. By being aware of the way we have developed our conception of death according to the education, the culture and the society we grew up in, we should accept the other and be capable of understanding "his world" of phenomena. On the basis of that knowledge we are able to develop an understanding of those we help and therefore support them in the most appropriate way.

Support and care from a practical point of view

"The most important, is to express yourselves as you are, without looking to adapt in a excessive or artificial way."

Shunryu Suzuki

In the contact with children or youngsters, when they ask a question, for example: "why do I have to die?" the most important is to give them an honest answer. You could say: "I can't give you an answer, but what do you think?" The answer could be an invitation to have a conversation that establishes our presence. We listen, we sympathise and we are there, very close.

When children talk of their situation, they need compassion and presence. A caregiver can express his feelings sincerely concerning the perspective of dying; death and mourning, if the child or the young one has already touch on the subject. When a child talks about his anxieties, we can ask him: "What are you afraid of in particular?" We can answer the child's question with another question to continue the conversation.

But also, small common actions such as drawing, mending things, reading, listening to music, watching videos can be ways of creating a contact, establishing a relationship and start talking. We have to be aware in care that according to age children and youngsters have different ways of addressing death. They develop according to their culture and education, different conceptions of death. In other words, we develop images, notions and conceptions to explain death. Between 6 and 10, children are particularly open to the subject of death. It is important that a familiar person who listens to them, to whom they can ask questions, who has time and

who is simply present, helps children. Children often feel guilty because they believe their thoughts can be the cause of what happens.

When a child had a fight with a family member and then thinks of that person's death, and if that person dies, the child will think he is responsible for that death.

It is important to clearly communicate that it is not his fault. After a conversation we can ask the child to repeat what has been said to outline what he understands. If the child remains disturbed it is best to carry on talking with him or her, talk of similar situations or look at picture books.

When a child experiences a family member's death, he can learn to deal with it no matter his age. He needs affection, attention, comfort and presence and sympathy from loved ones. Often parents are overwhelmed with their own mourning. Friends or other close adults may take on that role.

One can talk about death, if the child is ready or depending on his age, look for explanations in picture books or by going to a cemetery, or inviting him to take part in the organisation of the funeral...etc.

If the child has anxieties or an uncomfortable feeling, we think together of what would help him. There are different possibilities according to his age; for example cook a good meal, prepare a drink, smell pleasant fragrances, light a candle, all sorts of ideas. What is important is to provide a presence within a familiar set up.

Examples of practical experiences illustrating the care work with children

Luis

The diagnosis. A phone call to the children's ambulant service. I pick up and listen to the mother. She says that for 4 weeks she knows that her 4 years old son Luis was diagnosed with an incurable metabolic disorder and that his maximum life expectation is 10 or 12 years.

While I am listening to her, I ask myself the following questions:

- How is this illness going to evolve?
- What can we do?
- Is there a family in the department I can turn to and ask how things go?
- When is he going to die?

I cannot solve these questions. But I can listen actively and suggest a meeting. At that meeting I invite the mother of a deceased child whose diagnosis was similar. The mother comes, the two women talk, questions are asked and experiences shared.

For the mother who just received the diagnosis, it is a consolation to find out that someone else has gone through the same thing. Hearing the other mother's experience makes her feel better; how she reacted and got use to the diagnosis. The other mother also gave her advice and ideas

about the best way to handle the illness. At the end of the meeting, the mothers decided to keep in touch.

Afterwards, the family regularly took part in the family groups of the children's ambulant service, to talk. They also asked practical questions concerning the disability insurance or the possible leisure activities. Today Luis is 8 years old. His family is very active in a mutual aid group. They carry on along their path led by Luis.

Johannes

Breakfast at the ambulant service of the children's hospice care. A mother enters and tells us why she came. Her son Johannes is 5 years old. Since he was born, he has a form of leukodystrophy with physical and psychological limitations, and a short life expectation. He will die during childhood.

She wants to share, talk about options and how to address the every day life difficulties. The other mothers tell her about a volunteer who can care for her family once a week from the ambulant children's hospice service.

I become the coordinator for this family and the contacts deepen. A year later the mother tells me the state of her son has worsened strongly. She says he is hardly capable of eating on his own and she thinks he probably will not be able to learn how to eat again. She finds this new situation difficult to accept. I listen, ask questions and talk with other families who have experienced similar situations. We meet up.

The mother has to face the mourning of this child who used to be autonomous while eating, and even Johannes himself must do the same, because he always enjoyed eating his sandwich by himself. Then she also has a younger daughter. She asks me for advice on how to deal with this situation. In our service there are trained volunteers. So I suggested one of them comes to play with the daughter once a week or comes for tea and talks with the mother of difficulties, wishes, expectations and every day life. The mother agreed and we organised it all. Now we see each other regularly to find out if the support is going well or if something should be changed. Today Johannes is fed by intubation in his abdominal wall. The food is injected. When the little sister Juliane goes on walks with the woman volunteer, she takes her doll and a little something to eat for it. When the doll is hungry, Juliane pulls out a syringe and injects it into the doll's belly...

Lukas

Assistance to a family with a child who has cancer. Lukas is 10 years old. Two years ago he was diagnosed with a brain tumour. The mother told us that after one-year treatment he got better. He had to do check ups every 6 months.

But before the first check up Lukas was not feeling well and the mother noticed unusual things. The check up confirmed 3 tumours in the brain and metastasis in the backbone.

A proposal of chemotherapy and palliative care was made. The mother agreed and in addition looked for the support of a children's care centre. It was her way of dealing with the diagnosis. She often talked about the evolution of Lukas' illness and described the here and now. The support was launched in "the here and now". During the last five months, two volunteers cared for Lukas, his sister and his mother. The father did not live with the family. The palliative service also brought him support, and later just after Lukas' death, so did we. We listened, sympathised and were simply present.

During five months we had long phone conversations with the mother. We talked about the process of dying:

- "Will he be in pain?"
- Do we have enough painkillers?
- Can we keep him at home?"

We also spoke of the funeral:

- "How and where can he be buried?"
- Will I come to an agreement with my ex-husband?"

The family was well prepared. I think Lukas was too. Two days before he died we went to visit him and Lukas was peaceful, in bed. He hooked up his little finger to mine and gently shook his head. It was a wordless farewell.

During the following days, the family organised the funeral without us. They just asked us to prepare balloons with cards and to release them after the memorial service.

Mourning support

In principle mourning is natural. The way children experience mourning allows us to observe it's natural side. Children cry, scream, are furious or on the contrary very calm. They have a stomach-ache or feel like nothing or cannot concentrate. But the following moment, confidence returns, they run on the lawn and play with a ball. The moment of mourning comes and then goes.

Roland Y. Rech taught in a mondo: "To practice zazen helps us better assimilate every day life emotions. That is to say, not to reject them when they emerge but to feel them and give them space. When we are sad, we are completely sad. We go to the end of grief and then let it pass by. It's like a cloud that passes by. It doesn't mean there are no clouds, but they don't remain, they pass by."

In general it can be said that we live through different phases in the course of mourning. These phases do not need to be definitely over or experienced in a specific order. Children and adults have different ways of mourning. Adults flounder in river water and children jump in paddles.

I find that the four mourning stages defined by the American William Worden give a good description of the mourning process:

1. To accept the reality of loss at the mental and sentimental levels
2. To go through the pain of mourning
3. To adapt to an environment in which the deceased is no longer there
4. To give a new place to the deceased and turn towards one's own life

During that period of mourning, rituals are a good source of strength, energy and support.

Vincent

To die

Monday, 24/01/11 (today is the memorial day): after the sesshin with Roland Y. Rech, I returned to work as a coordinator and with a colleague we went to an organisation meeting. Then there was a call from the family: the sister of the mother informed us that Vincent had died during the night.

Vincent was 13 years old. He was seriously handicapped and had a short life expectation. But until then he had been stable and we did not expect him to die. Like every morning, his twin sister Anne left for school, then his Mum went to see him in bed and he was dead.

The mother asked us: "How to tell his sister Anne?" She had come back home for lunch and did not suspect it. We went to see them straight away to give them our support.

When we arrived, an undertaker was already in the bedroom and Vincent's body was in a body bag. The family members were in the corridor crying. I asked if I could see Vincent. The mother allowed me to go in the room. The bag was already closed but the undertaker opened it so I could bid farewell.

Later the mother asked me how Vincent looked. I gave her my impression: a perfectly calm boy sleeping peacefully. It was an important answer for the mother because she was feeling guilty for not being on Vincent's side when he died. She could not bear the thought that Vincent might have suffered. Many times, the same day and the ones that followed, the mother asked me the same question: "How did Vincent look?"

Anne returned to school. The family had told her that Vincent had not woken up that morning, that he was asleep and had died, and that the undertakers had taken him away to bury him like their dad. The family were hugging and crying. My colleague and I were with them, present and ready to answer any questions or demands. We sat around a table for tea and talked. Anne said she had taken care of Vincent a lot, the day before and it did her good to talk. We were hungry. Anne and I went to the bakery to buy a cake and we talked about the funeral. She could not decide whether she wanted to take part in the funeral. Suddenly we ran, got the cake and ran back to the house although Anne is not very athletic and does not like to run. We had a cup of tea and ate the cake. We lit a candle for Vincent and spoke of the evening.

What does the family need to be comfortable at home and sleep well this evening?

With the help of an aunt and of the neighbours they found a solution. Then we left the family and promised to call in the following days.

The organisation of the funeral is different in each family. By talking we try to find out what is best for the family. The planning for Vincent was decided. He was to be buried like his father who died 5 years earlier. Support was not necessary. I made the suggestion of releasing balloons from the grave as a farewell. The mother and the sister liked the idea and Anne finally agreed to come to the funeral.

The funeral took place on the Thursday.

The balloons were prepared and distributed after the ceremony. At the grave each one released a balloon. Anne was very sad and cried a lot. The members of the children hospice care service were by her side. The rest of the family was also sad. We kept very close to one another.

We accepted the invitation for coffee after the funeral. We listened to and answered many questions. Everybody remembered the father's funeral; it was like a flash back. We, the members of the children's care service, were considered like the ones who know how things take place. We were the ones giving strength to Anne and her family.

Afterwards there were still many meetings with Anne and her mother. A female volunteer went to see Anne once a week to talk or do something with her.

Taking care of oneself

The most important to take good care of oneself, is to always think of who we are and how we relate to ourselves: "how do I position myself in life to confront suffering, the fact of dying, death and mourning?"

Be aware of our own wishes, needs and take good care of them.

"What support do I need to be able to care for others along the way of life?"

My path

I have come across a lot of emotions. The Way has helped me find the energy. The practice of zazen, in the group or during the sesshin gives me strength. To help me in my work, there are two very important ceremonies during a sesshin: the kito and the ceremony for the dead. The energy of those ceremonies helps me to bid farewell to those who are deceased and send energy to those who are seriously ill. The rituals make me realise clearly how we are part of a whole. Our relation to the cosmic order becomes reality.

I also try to stay in good shape by eating healthy food and doing exercise in a natural environment. Family life and friends support me in my strength.

Last May I gave up my activity in the ambulant service because my family needed more attention. Today I