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# Death of a child on the threshold of a new life and support for the bereaved family

## Śmierć dziecka na progu nowego życia i pomoc dla pograżonej w smutku rodziny

### Abstract:

*Although modern medicine reduced the amount of child deaths significantly, it cannot save the life of every child. As an outcome, a death of a child is perceived as something completely abnormal now. The article discusses the situation of families, who lost one of their children, and illustrates it by examples from our practice of health care chaplains. It also presents the support for these families available in the Czech Republic.*

**Keywords:** *death of a child; mourning; grief counsellors; health care chaplains.*

### Abstrakt:

*Chociaż współczesna medycyna znacznie ograniczyła śmiertelność dzieci, nie zdołała ocalić życia każdego dziecka. W rezultacie śmierć dziecka jest obecnie postrzegana jako coś całkowicie nienormalnego. Artykuł omawia sytuację rodzin, które utraciły jedno ze swoich dzieci, i opisuje je przykładami z praktyki kapelanów opieki zdrowotnej. Opisuje również pomoc dostępną dla rodzin w Republice Czeskiej.*

**Słowa kluczowe:** *śmierć dziecka, żałoba, terapeuci żałoby, kapelani opieki zdrowotnej.*

According to statistics, approximately 520 children die annually in the Czech Republic before their birth (after the 22nd week of pregnancy) or up to one year of age (e.g. in 2012, the natality was 108 955, the feto-infantile mortality 4.8, cf. ÚZIS ČR 2013, 7 and 65). Most of the deceases occur abruptly. The lives of the af-

flicted parents is unexpectedly and permanently changed. Nonetheless, the loss hurts other intimates as well, particularly brothers and sisters, grandparents and friends. The bereaved experience extreme pain and deep grief. They need help and support to be able to accept their situation and to go on living.

The aim of this article is to provide deeper understanding of the situation of those families who lost their child. Furthermore, it describes the care they are provided in the Czech Republic. All of it is illustrated by three case studies from our practise of health care chaplains.

## 1. Death of a Child

The process of dying and death are always traumatizing events in the family life. This is especially true when the death affects a child. The immense progress of medicine in care for newborns shows here its downside: we are not prepared to accept death of a baby, we consider it to be something unjust and inadequate. A century ago, both natality and mortality of newborns were higher. All parents saw child losses in their surrounding and counted with it to a certain degree. They also saw how other parents coped with their losses. Medieval castles used to be equipped with special caskets for stillborn babies where they stayed by their mother overnight. Today, a child has become “sacralised” (Black 2013, 744–745) and his/her death seems to be unprecedented and often unexpected event.

There are three situations, how the death of a child on the threshold of a new life can occur. Firstly, the child may die already before his/her birth. Secondly, the child may be born with a congenital disease and his/her parents know for a long time that he/she would die. Finally, in other cases it is not until a certain point that everything goes wrong and the child dies unexpectedly. Each of these incidents is specific and the parents response to it with slightly different emotions. Nevertheless, the pain over the loss of their child remains immense in all the cases.

### 1.1. A death of a child before birth

If a child dies before the birth in a consequence of a spontaneous abortion, it is traumatizing most of all for his/her mother. She was the only one in a direct contact with her baby. Still usually it was not only she, but also the father who looked forward to their daughter or son. Others, however, perceived the child as “less real”, if they knew about him/her at all. That is why the parents often feel especially alone in their grief.

As fathers are increasingly involved in the care for their children and also in the preparations for the birth (they talk to their babies in the belly etc.), their emotional bond becomes stronger. The father of a child who died from spontaneous abortion may feel in the grip of his own bereaving on one side and of the care for his wife on the other side. He can even think that his own expressions of grief would make the situation only worse (Slee 2002, 261). This is, however, not the case and the mother needs to know about his emotional response. Nevertheless, both parents should not forget the feelings of their other children. If the siblings were informed, they must cope with their disappointment as well. If they were not, the parents must decide whether and when to tell them.

What the parents need from their relatives and friends is that they do not make taboo or light of their misfortune. On one hand, the death should not be trivialized as if the child was not real. The mother experienced the existence of her baby and looked forward to him/her – together with her family. Sensitive and unobtrusive concern is highly appreciated. On the other hand, people in the surrounding should avoid manipulating the parents into certain interpretation of their situation, for instance by saying that there is one more little angel in the heaven. It is up to the parents which interpretation they choose.

Another traumatizing experience is when a child dies in the mother's womb and she still has to give him/her birth. Some women describe their feelings as if they became a coffin for their child (Henley, Kohner 2001, 82). They may tend to "quick solutions" and want to induce labour as soon as possible. The medical stuff sometimes support them in this decision. Nevertheless, if they postpone the birth for a few days, they gain time to think the situation through and make decisions they would be content with in the future, i.e. the decisions about the course of the delivery, about the short time with their deceased baby afterwards and about the funeral.

Peter L.,

(died before birth, parents live together in a marriage, one 5-year-old brother)

The course of pregnancy was normal up to the 38th week, when a gynaecologist examining the mother could not hear the heart sounds of the baby. He sent her to the maternity hospital, where the death of the baby was confirmed. It was probably caused by a heart failure, because there was a genetic predisposition in the family. The mother was in shock. She expressed her extreme pain and inability to understand what had happened. As she said, she was terrified by the idea of giving birth to a dead child, because the delivery should be a gate to life, not to death.

Physicians induced labour. They allowed the father to be present to support his wife. When a boy was born, the midwife washed and dressed him. The parents were

given time to say goodbye to Peter according to their needs (approximately one hour). They could take the child in their arms and caress him. Then they confirmed that they do not wish the autopsy. Their will was respected.

The father of Peter, a joiner, made a coffin for his son. (According to Czech law every coffin needs an authorization from a funeral home, which was accomplished.) The funeral consisted of a mass and of a ceremony in the cemetery. All the family and close friends were present. The father carried the coffin and put his son into the family grave.

In this case, the family was given the opportunity to say goodbye to their child. It helped the older son to view Peter as a brother, who died. Peter was given a name and a place in his family. All relatives and friends could experience that he lived.

For the subsequent process of bereavement, it is important that the dead child does not end up in the hospital waste, but that he/she is treated as a deceased person. Though this has become more common in recent years, it is still not the rule in all hospitals in the Czech Republic.

## 1.2. A baby suffering from a birth defect

Sometimes physicians diagnose a serious illness before or short after the birth. The death is inevitable, but not immediate. This group of children suffering from life-limiting illnesses increased in last decades because of developments in technology (Black 2013, 745). Such trend has both positive and negative effects. On one hand, children with life-limiting illnesses can live longer and also their parents are granted time to prepare for the death. If the family desperately needs more time to prepare for the inevitable end, the physicians might even try and keep the child living a bit longer, even if they already let him/her die under other conditions. On the other hand, the effort to prolong the child's life becomes ethically problematic if it turns into stubbornness. If the hospital continues aggressive treatment beyond any boundaries and follows the motto "No fetus will defeat us", the suffering of the child is unnecessarily prolonged. In this case, especially the nurses, who spend with the baby more time than the physicians, may disagree with the policy of the hospital and feel frustrated (Bloomer et al. 2015, 90).

Nevertheless, the parents are usually exposed to uncertainty at first. The outcomes of the examinations might be ambiguous or might require a double check. The prognosis also might be uncertain and there is always the possibility of mistake – at least to a certain point. Even if an error is out of question, the

emotional response of parents goes through several stages including the stage of denial, when they stick to the possibility that everything is a big mistake (Kübler-Ross, Byock 2014, 11–35). It is a natural and necessary process heading to the acknowledgement of the painful news.

Jacob D.

(died in two month on encephalocele, parents live together in a marriage – both in their late thirties; the oldest sister is in a good health, two other brothers had already died of the same disease)

A health care chaplain was contacted by a nurse who explained that Jacob, two months old, is in the Intensive Care Unit and his mother wishes him to be baptised, because his life is in danger. Jacob died one week after the baptism. The parents experienced it as the end of their hope to have one more healthy child because of their age and of the hereditary disease afflicting all male descents.

During the last Jacob's days, the couple were devastated, but able to speak about their grief. Mother held often her child tight as if she wanted to protect him from death. Both parents were afraid whether Jacob had pains (they were assured that not). They also discussed the question of the suffering of innocent and the question "Why?"

As soon as the parents realize that something turned wrong, they start to ask countless questions. They need someone to discuss these questions with without being told ready-to-use answers. This partner can be a psychologist, a health care chaplain or a priest.

### **1.3. A child dying unexpectedly**

If the child is dying unexpectedly, the parents are put into an extreme situation. Their mind is not given the necessary time to process the events. The bad news is paralysing. All the involved people experience fully, how the death of a "healthy" child contradicts our human comprehension.

The situation is difficult also for other children in the family, who feel that something wrong is happening (Henley, Kohner 2001, 86–91). If they are told about the upcoming death of their sibling, they may react aggressively. If they were told that their brother or sister is having tummy ache, they may start to fear of death as soon as they have tummy ache. If the death is explained to them as a sleep, they might be afraid of falling asleep (Henley, Kohner 2001, 87).

Oto V.

(born with muscular dystrophy, died in six months; mother, 37, father, 52, older preschool brother)

During the whole pregnancy, everything seemed in order. Nevertheless, Oto was immediately carried away after the delivery. The mother became scared being not allowed to see her child. One of the physicians returned later and examined the physiognomy of her face and even took pictures of her. He questioned her about degenerative diseases in her family. An hour later, the mother was given the child and told the diagnosis of muscular dystrophy. Oto looked like a puppet. His prognosis was uncertain, he could live several months or years.

The mother was in shock because everything had gone right up to the birth and she had been ascertained from everywhere that the child was going to be healthy. Oto spent six weeks in hospital. His family was well off, so they equipped their home with the necessary devices and took Oto home. The whole family was engaged in the care for him. When winter approached, they decided to leave for Thailand where the climate would suit better Oto's needs. Oto died there, he was cremated and his remains were brought to his homeland.

As long as Oto lived, his parents spent all their strength on the care for him. When he died, they had suddenly plenty of time to think. Especially the father worried whether he had failed to do anything for his son.

Whatever sacrifices the parents brought for their child, they usually need an assurance that they did everything they could.

## 2. The family and close friends experiencing loss of a child

Each of the persons involved perceives the death of a child in a different way. The way they go through this experience affects the subsequent process of bereavement and the ability to accept their loss.

Understandably, it is the mother who has the closest bond to the child. She spent the pregnancy with him/her, she felt the motions and she was the first one who heard the cry of her newborn. She is usually also the first one who is told the diagnosis.

Occasionally, the mother tends to deal with everything on her own at first, because she has a feeling that nobody understands her and nobody can help her. Gradually, she learns how to speak about her situation with others and she needs to express her feelings over and over. It is crucial that her husband listens to her in this moment, even though the discussion spins in a circle without any

progress. The mother also needs to see father's emotions in order to feel that she is not alone in the grief. Unfortunately, some men worry that it would be perceived as a demonstration of their weakness or helplessness (Henley, Kohner 2001, 69).

Sometimes the parents may switch their roles. If the father is collapsing, the mother can take the role of the stronger one, but as soon as he is by his strength again, she can afford to be the "weaker" again.

The wish to baptise Oto came from his father. During the ceremony, the mother did not tear whereas the father repeatedly fell to his knees and wept loudly. He expressed his feelings: "The life is beginning, but in what shape?" He had been looking forward to a healthy child and did not count with the possibility of having a disabled son.

The mother was "the strong one" in the beginning and supported her husband. Nevertheless, their roles changed after the first moth. The father engaged in the care for Oto, into the exercises and massages, whereas the mother became depressed. She could be the weaker now and lean on her husband.

In other occasions, the mother acts as if nothing happened. For instance, she starts to tidy the children's room after the funeral as if her child were to return home from a visit to friends. In other words, she goes through a strong phase of denial (Kübler-Ross, Byock 2014, 11-35). Other mothers feel guilty and ask themselves: did I do anything wrong? Could I do anything better? They constantly return to the death of their child and ask for more information. They also face feelings of anger and injustice: "Why did it happen precisely to me?" Some of them cannot endure seeing healthy children and their happy mother around (Henley, Kohner 2001, 67).

In contrast, fathers usually do not show their emotions so apparently, but they have them and keep them inside. When they are not able to verbalize these emotions, they can still express them through some activity (Stroebe, Schut, Finkenauer 2013, 31), especially physical.

The father of Peter made a coffin for his son and carried him during the funeral in a similar manner as his mother carried him during pregnancy. This helped him to accept his new role.

In case of men, it is even more common that they are bothered by remorse and questions if everything was done correctly. They think over, "what would have happened, if..." In this moment, honest communication between

the parents is necessary. The wife should not strengthen the remorse or trivialize it.

Still, the parents cannot focus only on themselves, especially if they have also other children. On one hand, every child needs a stable environment, but on the other hand, every disease or death of a child afflicts the inner family rhythm. The parents are suddenly silent and tearful. If they have already other children, it is necessary to restore the normal running of the family life, so that these children could see their parents as they know them.

The parents of Oto focused their whole attention on their sick son, whereas his older brother was set aside. His father repeatedly sent him away, "Go away from him, don't touch him!"

It is always difficult for the parents to talk with their child about death. Nevertheless, the child has many questions and he/she needs someone to discuss them with. If nothing else, the child would be asked by classmates and he/she needs to know how to answer.

The death of a child does not affect only the living brothers and sisters, but also those, who would be born in the future. The next child may live in the shade of the deceased one.

When mother of Oto became pregnant again half year later, the parents (especially the father) spoke about reincarnation a lot, despite their Catholic faith. The newborn son was called Oto to resemble the name of his older deceased brother.

Every child needs to be perceived as a unique person. Yet this is not the only danger for siblings. If there is only one living child in the family, no matter whether older or younger than the deceased one, the parents may stick to him or her in an unhealthy way, because they are afraid of losing him/her.

The grandparents are not affected as directly as the parents, but they are older and may suffer from their own illnesses. A danger exists that they would transfer their own anxieties on the parents. They could afflict the parents by questions, "Did you not neglect anything?" or "Could you prevent the death?" These questions may be felt as rebukes and lack of understanding and lead to an isolation between generations.

Older grandparents may ask why the child died and not them. They need assurance that both parents and the medical staff made everything possible. The questions "What if...?" have no sense and only increase the pain.



Also the friends are close to the bereaved parents (at least by their age). They should not avoid the bereaved couple, but offer them a visit or a shared event. It is very probable that the parents will open their heart to them.

When the remains of Oto were brought to the Czech Republic, his parents organized a funeral mass and invited all the physicians and nurses who took care of their son. Those who came could not only take part in the ceremony, but also participate actively (readings from the Scriptures, prayers, bringing up the gifts).

Oto's parents invited not only their old friends, but also those who cared for their son during his hospitalization. The contact may be helpful for both parties. Especially the nurses spend a lot of time in the contact with the child. Despite that, they cannot freely express their opinions during the treatment, but only influence the doctors (Bloomer et al, 2015, 88). Confronted with the suffering of a child, they may want to engage beyond their normal duties. If the time limits and amount of tasks, however, prevent them from doing some "little extra" for the child, they might experience bad conscience, tiredness and burnout (Furingsten et al. 2015, 184).

### **3. Possibilities of support for the bereaved family**

Experience shows that both parents should take time to say goodbye to their child and to cradle him/her in their arms (especially when the death was unexpected, cf. Dohnalová, Musil, 111, 2008). It is also beneficial if they retain some physical memento, for example a hair lock (Henley, Kohner 2001, 79). The staff of intensive care units offer even other more sophisticated possibilities, such as a footprint or handprint. They can also take a fingerprint for making funeral jewellery. Most hospitals allow parents to manage a baptism ceremony for their child or to say goodbye to him/her in private.

The baptism of Jacob became a solemn ceremony thanks to the cooperation of all interested parties. While the health care chaplain arranged a priest, one of the nurses prepared a room equipped with a table covered with a white cloth. The father was also present. When the ceremony was over, the father assisted the priest with filling the forms, whereas the chaplain paid attention to the mother and her child.

In this case, the cooperation between the hospital staff, health care chaplain and priest worked really well. It proved to be helpful that the health care chaplain

was a woman. She could stay closer to the mother, whereas the priest supported the father as a man and offered him some sort of activity, which he needed.

Certain hospitals employ health care chaplains and grief counsellors who accompany one of the parents or the whole couple through the process of bereavement. They assist parents in identifying and expressing their feelings and give them the assurance that their feelings are normal. They may also help the couple to overcome a crisis, because death of a child inflicts conflict situations and increases the risk of divorce (Lyngstad 2013, 79–86). The aim of this assistance is to help the parents to unfasten from their deceased child, to accept their loss and to adapt to the new reality. Both bereaved people and the hospital staff still learn to use these services.

Other times, however, the families are provided with care as long as their child lives, but this care ends with his/her death. Many hospitals employ child psychologists who assist also the whole family – but only as long as the patient lives. Some hospitals provide counselling for bereaved people, e.g. the University Hospital in Olomouc recently opened counselling centre Hořec (“Gentian” – blue mountain flower whose name evokes Czech word for “grief”). In this and similar centres, trained and certified workers provide their clients with a range of services: assistance in preparation of funeral, assistance in acceptance of the loss of a close person and also a safe place to express feelings of anger, fear or powerlessness.

Nevertheless, families who lost a child need a long-term support from those who experienced the same trauma. This support was largely missing in the Czech Republic until 2005, when Martina Hráská and Bibiana Wildnerová founded the association *Dlouhá cesta* (“Long journey”). Both founders went through the experience of loss of a child and they sought a meaning for their life (Dohnalová, Musil, 107, 2008). When they realized how helpful was to share their stories and challenges with other bereaved mothers, they decided to found the association. The mission of *Dlouhá cesta* is “to support both psychological and practical mothers and families, whose child died, and to improve gradually their psychical and physical condition” (Dohnalová, Musil, 108, 2008).

*Dlouhá cesta* runs a whole variety of projects. First of all, they offer peer counselling. Generally speaking, peer counselling suffers from certain disadvantages in comparison with professional counselling. Peer counsellors are not trained to discern and adequately treat more complex issues such as depression or addictions and they are more likely to transgress the proper boundaries in the relationship (Špatenková, 2013, 17). In the care for bereaved families, however, their work is irreplaceable. The parents are more likely to have confidence in someone who went through a similar experience and who can therefore understand them.

Apart from individual consultations, Dlouhá cesta offers also support in self-help groups emerging around children's hospices. These groups offer a space for sharing experiences and life stories. Regular meetings help the bereaved parents to overcome their feeling of isolation, loneliness and despair (Bužgová, Duračková 2015, 27).

Internet counselling is another, more anonymous eventuality. Dlouhá cesta runs one internet counselling service called Prázdná kolébka ("Empty Cradle", [www.prazdnakolebka.cz](http://www.prazdnakolebka.cz)). The web site offers information regarding funeral management or dealing with authorities and experience exchange with other families who went through this situation before. Prázdná kolébka offers also e-learning courses supplemented by seminars for midwives and social workers and other staff who could come into contact with perinatal death of a child. The object of these courses is to teach professionals how to communicate with parents.

Nevertheless, the activities of Dlouhá cesta do not limit to counselling. Two successful projects were inspired by TV shows. A project called "Stále jsi žena" ("You keep being a woman") offers one mother a style change. Mothers can take part in a lottery and the winner gains a style change performed by a dresser, a manicurist and a photographer.

Similarly a project called "Barevný anděl" (Colourful angel) focuses on the siblings of the deceased child. It helps families to renovate the children's rooms in their homes. The aim of this project is to help the children to start a new stage of their life without their brother or sister. The whole family should take part in the renovation in order to promote mutual communication.

Some families, however, choose completely different strategies:

The parents of Oto decided to keep his urn at home instead of placing it in cemetery. There is also a big photo of Oto in the children room.

Apart from the activities run by Dlouhá cesta, there are certain events in the Czech Republic which transcends the scope of only one association. The "Worldwide Candle Lighting" is organized in many places by a different subject. This annual event was initiated by international society Compassionate Friends. Originating in the USA in 1997, it spread all over the globe including the Czech Republic. Every second Sunday in December, families meet and light a candle for their deceased children.

The parents of Oto take part in the World Candle Lighting event, but they also lit the candle at home every day. On Christmas, they set the table with one extra plate.

Annual ceremonies may help families to remember their deceased children and then to return back to their normal life (Henley, Kohner 2001, 78). If parents, however, exaggerate these ceremonies and repeat them every day, it complicates and prolongs the process of mourning.

## Conclusion

As Europeans, we are happy to live in one of the most developed area of the world. Thanks to the excellent health care and health insurance, the mortality of children is minimal. Nevertheless, even our health care system cannot save all children from dying. No one can. That is the reason why we must not only constantly improve our care for children, but also for bereaved families as well.

The quality of care for bereaved parents offered by professional staff in Czech hospitals is gradually increasing. Despite some exceptions, they are well trained how to react and assist the families. Also the cooperation between the medical staff, health care chaplains and priests is developing promisingly. The same cannot be said about the awareness of the issue in the general public. We still need to increase the awareness in the society about the proper communication with the bereaved families.

In this respect, we can take the inspiration by physically disabled people. A significant progress has been achieved in the education about the needs of blind people or people in wheelchairs. Similarly, we should raise the public awareness about how to approach parents and siblings of deceased children. After all, good manners are not limited to the proper behaviour at table. They include proper conduct towards bereaved persons as well, especially those who lost their child.

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