

# **Understanding loss and grief-dynamics following the diagnosis of disability**

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## **APPENDIX – Guide for casemanagement in griefcounselling**

### **Reference**

# Understanding loss and grief-dynamics related to the diagnosis of disability

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## Summary

A client<sup>1</sup> with complicated grief – for example, following the diagnosis of disability – may experience the so-called Unfinished Business Syndrome (UBS). This can be explained as a smouldering peat-moor fire, which burns underground setting off new symptoms at the surface again and again (*Mönnink 2008*). In this chapter, it is suggested that early attention paid by professionals to the loss-related responses and complaints of clients or their families can prevent UBS by facilitating the coping process in clients coming to terms with their losses.

The chapter further indicates how the study of loss and grief can be beneficial to the caring professions when confronted with grieving clients. This study helps the helpers acknowledging three succesfactors in the griefprocess: 1. Grief-impact, 2. Grief-coping and 3. Grief-support. Professionals who help families to reduce negativity and empower positivity in these three factors, help clients to become aware of the grief-impact, to cope effectively with the grief involved and strengthen the social network-support. To ameliorate the quality of multidisciplinary cooperation, also the ‘Guide for casemanagement in grief counselling’ – is introduced (see Appendix).

The key issue in this chapter is the identification of effective professional interventions based on insights of impact of losses in life cycle, dynamics in coping with grief and in support within the family and by professionals themselves. These interventions are summarised in the Guide mentioned above. A case history (differentiated from the main text by the use of italics), written by Ed Nolens from his practice as a medical social worker, illustrates the theory described.

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<sup>1</sup> When ‘client’ is mentioned in the text it refers to the *client system* (i.e. ‘client and family’). In the case of a client who is unable to give consent due to their youth, permanent or temporary mental incapacity, etc., it refers to their parents, spouse and/or other relatives.

## **Introduction: impact, coping and support-dynamics**

*Perhaps we busy ourselves too quickly with finding a way out. Making room for loss experiences is essential, too. Or could this be too threatening to us?* (Professional at the Congress, 'Loss and Mourning in Nursing', November 2001)

Grief counselling dates back to around 1980, when the taboo against acknowledging the impact of loss on a person's mental health was diminishing. The supporting theory deals with systematising knowledge and skills for professionals in relevant occupations, such as nursing, medicine, social work and physical therapy. The premise of grief counselling is that people are able to – and can be enabled to – actively and consciously say farewell to the cause of their grief in their own way and at their own pace.

In coming to terms with loss, the client has 'griefwork' to do – characterised by Freud as 'Trauerarbeit'. While doing this, however, attentive support from understanding professionals seems essential. Whether it is saying farewell to a deceased loved one, to health (e.g. their own or their child's), to their job or to their homeland, clients in need may make an appeal for help from the caring professions. And this appeal will be more urgent if the client's own support networks are failing.

The study of loss and grief describes the processes likely to be associated with it, providing information

- on 'the *impact* of loss during the human life cycle' and
- on *coping* with loss as well as some knowledge
- on social network-*support* as well as supportive interventions by grief counselling.

So, this article offers answers to questions such as: what is the impact of all kinds of losses in the course of a human life and in professional practice? what coping processes can be seen and labelled normal or complicated with clients and in professionals? what kind of support is given in the social network to the families and what is the quality of selfcare of professionals? First the impact, coping and support are described on behalf of the professionals concerned with loss-cases. Second, the dynamics of loss and grief in the sense of impact, coping and support are described on behalf of the clients. At last the questions is answered: what are the responsibilities of health care agencies in relation to loss and grief counselling? How does a guide for casemanagement in griefcounselling look like?

## **Impact of loss in professional practice**

*Robert was born seven years ago after a problem-free pregnancy and a home-delivery. A few weeks after his birth, problems with his eyesight were found. At 18 months, Robert's parents noticed his movements steadily weakening, and when he was three years old a brain tumour was diagnosed. In the following year, Robert spent more time in hospital than at home, having to endure chemotherapy and radiation therapy. When at home again, he fell ill after a few months and eventually ended up in the university hospital once more. A penicillin cure administered to him by a regional hospital had caused an eight-day coma. The university hospital diagnosed meningitis, with possible blood-poisoning, resulting in brain damage. One of the consequences was a left-sided hemiparesis.*

*Robert's parents had to go through two horrible years, witnessing the process of their son's health going downhill within a short time. The fear of losing their child was immense, and has never left them completely. Each night, the parents still make sure that Robert is sleeping peacefully and not having an epileptic seizure. In our talks, it became clear that they were still experiencing a lot of anger about the way they had been treated by some of the hospital staff. These topics were among the first to be addressed.*

Loss confronts us with the limits and boundaries of life. The consequential feelings of vulnerability are universal, as is professionals' sense of discomfort at the confrontation with loss in their practice. Yet, in these modern times, there seems to be a complicating factor.

### **Impact of loss: professionals may feel powerlessness**

We lead our lives in an era of autonomy and control over a great many areas of life. This autonomy is a result of immense medical and social progress. Around 1900, life expectancy was only about 40 years. To modern people, the idea of autonomy in life has brought about an illusion of control and invulnerability that is shattered when we are confronted with loss. In many cases, a cure cannot be effected. When physicians, counsellors and other paramedic professionals are prepared only for healing – for the positive outcomes of health care – their feelings of discomfort in the face of incurable cases are bound to be strong.

Professionals trained in grief counselling take for granted that healthcare is not only about healing, but about loss, too. Having learned to shift perspective from cure to care when appropriate, they can work from *both* the diagnosis-prescription model *and* the experiential counselling model. In experiential counselling, professionals are equipped with a range of techniques that enable them to provide care when cure appears impossible. There are many areas in nursing where griefcounselling is already being given. In hospices, palliative care is a form of experiential care for the dying; in psycho-geriatric care, validation and reminiscence therapy are examples of experiential care; in primary care, too, the experiential care model is gradually gaining ground again. In short, the theory of grief counselling and training in associated techniques, provide professionals with the understanding to provide adequate care for clients who are confronted with loss and grief.

### **Coping: professionals may victimise families**

In the process of mastering grief counselling, professionals become aware of the personal parallel process between themselves and their clients. For example, as the client expresses powerlessness and sorrow, the professional may become personally affected by similar feelings. During training, the professional is made aware of this phenomena of transference and counter-transference. Professionals who are not familiar with these phenomena may be ineffective in caring for the client.

*Robert was now attending school. Quite suddenly, and despite positive reports (according to Robert's parents), they received a phone call from the nursery school teacher during the summer vacation, who asked them to put in an application for a place at the Mytyl School for children with learning disabilities at the rehabilitation centre. It soon became clear that social workers had also been involved in this decision, having already started the process of preparing a possible placement at the Mytyl School. Reluctantly, the parents went for an introductory talk. Robert had also strongly resisted the idea of changing schools, they said. As they felt they had their backs against the wall for want of a good alternative, they went along with the placement. There was an initial screening carried out by the rehabilitation physician, who then introduced them to the teacher. Robert started out in the nursery class, and after a few weeks was introduced to the physical therapist, the occupational therapist, the speech therapist, the child psychologist and the social worker. Then there was a meeting. Present were the child psychologist, the Mytyl School social worker, the parents and the paediatric team social worker.*

A professional who is *not* properly trained in grief counselling can exacerbate their client's grief by using an ineffective approach. This will result in the so called 'secondary victimisation': the client – already victim of the diagnosis - becomes a 'victim' for the second time through the actions of the professional. There are five patterns of behaviour by professionals recognised as likely to result in the client's being 'victimised for the second time'. These are Rescuing, Accusing, Avoiding, Distancing and Brainwashing.

In the **rescue** pattern, the professional is preoccupied by his personal need to efface himself on behalf of the client. In this so-called 'Mother Theresa Syndrome', it may be that the client's actual cry for help is made secondary to the fulfilment of the professional's need to help. In the second pattern, the professional **accuses** the client of 'not responding properly' to the professional's 'rescuing' activities. The underlying message may be: 'You're absolutely fine now. I've given you a lot of attention. Your continuing grief is obviously a means of fulfilling your craving for attention.' The rescuing and accusing patterns are points of the so-called 'Rescue Triangle' of victim/rescuer/accuser. In this model, the professional has overstepped the professional boundary; they behave patronisingly towards, and become unprofessionally 'close' to, the client.

In the other three victimising patterns – avoiding, distancing and brainwashing – the professional keeps too great a professional distance between themselves and the client. For example, in the pattern of **avoiding**, the professional ignores clients whom, they feel, have become emotionally too close, thus avoiding self-exposure to such a client or situation. In the **distancing** pattern, the professional does not so much avoid contact with the client, as become intentionally distant, steering the client away from addressing the emotional needs they are communicating. In the **brainwashing** pattern, the grieving client is 'consoled' with the explanation that 'the situation is a challenge' or encouraged: 'Cheer up. It's all going to be fine. It's a beautiful day today, isn't it? Let's make the most of it.'

These five victimising patterns, while they may enable the professional to distance from the emotional side of their job, cause additional distress to the client. Better is preventing these kind of secondary victimisation by proper training in the study of loss and grief.

### **Support: who cares for the caregivers?**

The term 'self-care' is about care for all the professionals involved (e.g. nurses, general practitioners, social workers, pastors, grief therapists, child therapists and others) in supporting each other as colleagues. The premise is that caring for grieving clients is likely

also to impact on the professionals themselves. Alleviating the strain of the compassionate work will prolong their commitment and good health.

Besides the support of the head of department or immediate colleagues, self-care may consist of co-counselling between colleagues so that accumulation of stress/distress can be prevented – for example, in a weekly 60-minute session, two colleagues may take turns to listen to each other for 30 minutes each. Counselling between colleagues is a pre-emptive measure to avoid burn-out. Establishing a team of colleagues to be on stand by in case of more severe incidents can be very beneficial, too.

### ***Impact of losses on clients during the life-cycle***

*Loss is an issue that appeals a lot, because you're dealing with it every day.*

(Professional at the Congress, 'Loss and Mourning in Nursing', November 2001)

Professionals more often than not associate loss with death. However, there are many more loss situations in the course of a human life that also need to be addressed by the professional. These are not necessarily related to the ultimate loss (death), but to losing other parts of one's life structure, such as a limb or one's health. A professional who associates loss only with death may not pick up on other possible losses, and may underestimate their significance.

*The social worker of the paediatric ward had, together with Robert's mother, identified the mother's feelings of grief, and had recommended that she continue counselling with the school social worker, who could help her progress in the process of coming to terms with all her emotionally intense experiences. Robert's mother went along with this. In suggesting this contact, the paediatric ward social worker was clearly preparing to refer Robert's mother to a colleague for grief counselling, showing some reluctance to let go of her contact with the parent.*

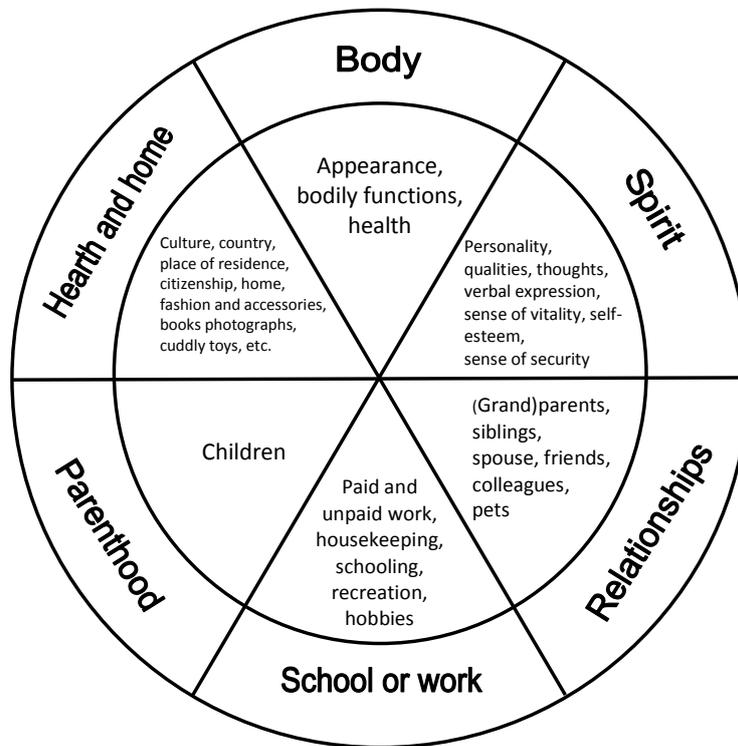
### **Loss situations in different life-domains**

Whether working in hospital or primary care, in general health or in mental health care, the professional worker, however young, is frequently involved in the many facets of loss:

miscarriage, stillbirth, cot death, birth of a child with a physical disorder, the death of a child, the diagnosis of a chronic disease, loss of mobility, amputation of a limb, burns and mutilation, menopause, climacteric complaints, divorce, inability to work, physical or mental decline, a growing incapacity, dementia and a sense of mortality. Apart from these direct losses, there are also some indirect manifestations of loss which impact on care practice, such as the uncompleted processing of previous losses (after war, adoption, abandonment, etc.), secondary losses that could stem from any of the primary losses mentioned above, such as loss of mobility, work, spouse and friendship, as well as deep-seated feelings of loss of independence, control, one's own dignity, pride or a future. Sometimes a loss can ruin someone's life, bringing about the feeling of their lives collapsing, or threatening to collapse, like a house of cards.

In Mönnink's book on the study of loss and grief – *Verlieskunde: Handreiking voor de beroepspraktijk* (2008) – the aforementioned losses are classified into six life domains (see figures 2 and 3):

- Body – appearance, bodily functions, health
- Spirit – personality, qualities, cognitions, verbal expression, sense of vitality, self-esteem sense of security
- Relationships – (grand)parents, siblings, spouse, friends, colleagues, pets
- School or work – paid and unpaid work, housekeeping, schooling, recreation, hobbies
- Parenthood – children
- Hearth and home – culture, country, place of residence, citizenship, home, fashion and accessories, books, photographs, cuddly toys



**Figure 2. The domains of life**

**Figure 3 Life cycle losses in each life-domain**

**Impact: the existential crisis following loss**

*After a loss, people contemplate the meaning of life. This may, from time to time, bring about a lot of anxiety and worries. (Professional at the Congress, ‘Loss and Mourning in Nursing’, November 2001)*

A loss may suddenly turn life completely upside down, disrupting and unsettling it. People are bewildered. They are thrown off balance. They find themselves going through a crisis. They feel damaged, confused. They say they feel as though they are falling into a black hole. According to the theory of loss, these people are experiencing an ‘existential vacuum’ which can trigger a truly existential crisis.

The void after a loss causes a psychological earthquake, vitally unsettling the client. They have been *fundamentally* damaged in terms of their sense of control, self-esteem, justice and perspective of the future. When a client’s sense of control has been challenged, they tell us they have lost their grip. When loss affects their self-esteem, they express it by remarks such

as 'I feel worthless/stained/numb/guilty.' When loss damages their sense of justice, clients experience feelings of unfairness, wondering: 'Why me? Why now? Why?' When clients feel that their future has been swept away, their perspective on their future has become disrupted. So losses damage the four illusions we cling of life: the illusion of control is damaged when losses make us out of control; the illusion of invulnerability is damaged when losses make ourself vulnerable; the illusion of justice is damaged when losses give us we did not expect and the illusion of future is damaged when losses take away of the perspective on the future we cling to.

Grief counselling aims to focus on this damage to the client's sense of the value of their life. The professional shows understanding towards the client, while together they estimate the damage done. The professional may ask the client to reconstruct past events, deal mindfully with the present situation, and develop attainable goals for a future that will be different to the one they had imagined. Various grief counselling techniques can be supportive, and, despite the fact that sometimes words fail to describe the loss adequately, the client feels they are being heard and accepted. Their emotions are regulated, giving them something to hold on to again. To conclude: the professional is aware that losses can touch our dream of our life and help us to grieve the loss of our dreams and help us reset the flight plan when a child is diagnosed with a disability (see: Welcome in Holland)

## **WELCOME TO HOLLAND**

by  
**Emily Perl Kingsley.**

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this.....

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland." "Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy." But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place. So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met. It's just a different place. It's slower-paced than

Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned." And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.

**1987 by Emily Perl Kingsley.**

To enable the client to overcome their crisis, a transitional period is needed from the 'old life' into the 'new life'. Coming to terms with loss is about letting go of the old and starting afresh in remembrance of the past. The client is encouraged to go through the pain of the loss in order to be able to establish a new equilibrium. To put it differently, processing loss is searching for a bearable new stability imposed on the 'shambles' of the loss. It is a process of transition, going from *unfreezing* (melting away the old equilibrium) through *moving on* (transition) to *refreezing* (establishing the new equilibrium).

Instead of living through their loss, many clients 'choose' to live their lives through denial. Such a survival tactic may temporarily bridge the gap caused by the loss, but it offers no lasting comfort. By seeking refuge in a displacement activity (e.g. in work, new relationships or alcohol and drugs), new problems are piled on top of the old ones. Instead of going through fundamental self-contemplation, these clients prefer to flee from the painful reality of the loss, which leaves them clinging to 'the old life' and stagnating.

### **Coping with loss: what responses to loss are normal?**

*When a client feels sad after a loss for a period of time, I would not consider this to be a depression. Yet, an increasing number of clients are prescribed antidepressants.*

*Natural sadness is labelled an illness much too soon. We should be normalising instead of medicalising responses to loss. (Professional at the Congress, 'Loss and Mourning in Nursing', November 2001)*

*Robert's mother gave the information about Robert and all the consequences of his poor prognosis in a somewhat cynical, humorous way, which is why I asked her if she*

*was using humour to keep herself on her feet. She agreed with this, stating that if she allowed any feelings to surface she would go mad! This made me ask whether she actually liked talking to me. She admitted to wondering if it really helped. I didn't go into this, and instead asked after the new pregnancy. 'Oh yes, that's also progressing, I guess'. She confirmed that she was feeling detached from her pregnancy. I said it was important that she should pay more attention to her unborn child. She did not reply to this, but said she would bring the subject up at our next session. In conclusion, I summarised our session, and together we imagined a personal archive box, and filled it with the following:*

- *Robert's horrible illness – cancer – and her fear of losing him*
- *On top of that the even more traumatic experience of Robert's eight days of coma, narrowly escaping death*
- *Having to face the fact that her child was coming home with severe damage: paralysis, epilepsy, near blindness*
- *Finding out that Robert was not going to be able to go to a regular school due to his brain damage*
- *Knowing that Robert had one blind eye and could see only 10% with the other one*
- *Anxiety about the future*
- *Her immediate worry about Robert not wanting to go to the Mytyl School*
- *Worrying about how she was going to raise a child who was so vulnerable*
- *Worrying that the new pregnancy was more than she could cope with at the moment.*

*The last item made her laugh and say: 'Yes. Let's not talk about that for some time to come, shall we?'*

*We made a new appointment, leaving the choice of subjects to reflect on in the interim up to her. I invited her husband to come, too. She did not think he would come. I had the feeling that she did not want him to come, and asked her if this was correct. She doubted that he would have time. When I asked whether the two of them had been sharing what had happened to them, she said that so far they had hardly done so at all; it was all too painful. I indicated that I would return to that topic with her at a later date.*

There is no standard response to loss. Naturally, a loss is very personal, as is the response to it. Yet, there is a range of predictable responses. An understanding of these responses is required for recognising the clients' symptoms and those of their relatives. The standard responses to loss are described (Mönnink, 2001) on an individual, communication and cultural level. Therefore, coming to terms with loss is no longer approached as a purely individual matter, but as a life-task, whether or not this is communicated to or shared with others: sympathy lightens sorrow.

The normal response to loss on an *individual* level is summarised in the concepts of Resistance, Farewell and Accommodation.

### ***Resistance***

In the resistance response, the client resists the pain of the loss by taking the sting out of the bad news. They may act as if there never was any bad news. Resistance to pain may take the shape of numbness, denial, dissociation, searching, merchandising or dismay. All these forms of resistance are shock absorbers keeping the painful realisation at bay.

### ***Farewell***

In this phase, the painful reality of the loss filters through, naturally causing all kinds of response. Beside sorrow, the normal emotions are anxiety, anger, hurt, disillusionment, depression or relief. In this response, people discharge their pain by crying with grief, trembling with anxiety and screaming in anger.

### ***Accommodation***

The client may mentally accommodate themselves to the loss. Just as the pupils in the eye accommodate to the varying intensity of light, the 'spirit' accommodates itself to the new situation. This is recognisable through a clients' well-considered decision to stop therapy, and their finding peace in their situation.

Resistance, farewell and accommodation are all normal responses to loss. They will not necessarily occur in any fixed order. Repeatedly, the client may slip back into resistance or sorrow or seemingly accommodate, adjusting to their new situation. According to current understanding, it is considered normal for a person to return to previous grief-responses in the case of 'triggering stimuli' such as birthdays, photographs, images on TV or sounds that remind them of their loss. Today, coming to terms with loss, therefore, is no longer considered to be the same as 'forgetting', but is seen as mindfully going on living, while

actively remembering the loss. Likewise, it is considered a normal phenomenon for grief to be re-activated.

*Robert's mother had remembered my remark about her cynicism; apparently she had needed somebody to tell her. It had affected her more than she had expected. We discussed this for a while, because it undeniably had a lot to do with all she had had to endure. She agreed she was very angry indeed about everything! She stated that she did not feel like focusing on this right now, but that she would rather talk about how to deal with Robert being difficult at home.*

*Things had improved remarkably at school, and she reluctantly admitted that she was having more problems accepting the Mytyl School than Robert. Yet her questions were directed more towards: 'How can I put Robert on the right track? How can I bring him up?' From what she told me it became clear she was feeling sorry for Robert and that it was hard for her to give him firm guidance. I indicated that, especially for vulnerable children, it was very important to create an environment at home in which they could feel secure, which set firm boundaries. It was Robert who ruled the place, actually, said his mother, giving a humorous account of what took place at home.*

*I became aware of my client showing less resistance, taking in what I said more easily. I told her so, and she confirmed that things had indeed become a lot better. The transition to the Mytyl School had evidently brought some peace at home after all.*

### **Family support in the three Os: Open acceptance**

The normal loss responses on a *communication* level are the responses to loss by the client and how they, and others affected, interact with those around them – spouse, siblings, parents, their extended family, friends, neighbours, colleagues, co-participants in a support group, etc.. The normal, communicated, loss-processing responses are represented by the 'three Os': 'Open acceptance' of the loss within the relationship; 'Order out of the chaos' caused by a loss in the relationship; and 'Orientation to the new future' together as well as remembering the past.

### **O rder in the chaos; O rientation to the new future**

An example of 'Open acceptance of the loss' is when parents, having lost their child, are sensitive to each other's responses and pain, sharing them and showing mutual understanding. 'Order in the chaos' implies that these parents pay attention to the lost equilibrium in their relationship, acknowledging that everything is different, not only on an individual level, but also in their relationship with one another. 'Orientation to the new future' is when the couple start making plans again, a 'prolonged' start together: 'Yes, this is how we can cope with it together.'

### **Destructive communication patterns**

Clients who have learnt to communicate adequately about their loss can effectively rid themselves of emotional strain. They can also find a new equilibrium within their relationships. However, communication about loss does not always pass off without complications. There are four ineffective communication patterns which interfere with the normal process of coming to terms with loss. These are 'Blaming', 'Self-blaming', 'Apathy' and 'Diversion'.

#### **'Blaming',**

People may have learnt to react by blaming others when suffering from pain and strain, implying that: 'Because of you I'm in pain now. It's because of you that I have to go through all of this.' An increase in complaints or blame for psychological damage could be based on this pattern too.

#### **'Self-blaming'**

The second ineffective pattern of communication linked to pain and loss is where the communicator blames themselves: 'I'm sorry, I am the one to blame for all this. No doubt it's my fault.' Clients seem to present themselves as insignificant and withdraw into themselves.

#### **'Robotic'**

The third such pattern after a loss is a distancing response, in which clients present as robotic, intellectualising the loss: 'After all, each loss is a challenge.'

#### **'Diversion'**

The fourth of these communications is 'diversion': changing the subject. Communication with a client who responds within the scope of one of these patterns often is not harmonious and takes up a lot of energy. Often, these behavioural patterns have been acquired at an early age or within the family, and are repeated in difficult situations.

*Outraged – that’s what Robert’s mother was about that doctor; through his actions, they had almost lost their child. I asked if this had been communicated to this physician. No, because this doctor had retired. Did they feel like filing a complaint after all? No – that would not be of any use. It would hurt too much.*

*Robert’s mother talked about the stay at the University Hospital following this episode and about the fears they had had that they were going to lose Robert. I explored this in detail. Her distress became visible. It was a mystery to her that Robert himself should remain so positive, although he frequently spoke with them about dying. I asked how this felt, being his parents. ‘Very odd, as if I’m talking to a grown-up. At moments like that I almost forget he’s a child’. It frightened her, though, and she always tried to change the subject.*

*She described how delighted they were when Robert came home from the hospital, but, at the same time, how upset they had felt about him having so many difficulties compared to other children:*

- *A drain in his head*
- *Epilepsy*
- *The need for growth-hormones due to permanent brain damage*
- *Difficulties with walking, hemiparesis*
- *Very bad eyesight*
- *Medication for a non-functioning thyroid*

*... and yet he was a happy child.*

*The attention paid by Robert’s mother to her unborn baby had become positive, enabling her temporarily to shut out her earlier misery. We made an appointment for me to make one more house call, together with the paediatric psychologist, before the new baby’s birth and observe Robert. She appreciated this very much.*

*We admired the new nursery and had the opportunity to watch Robert with his family. Surprising to us was the behaviour of the father who, without hesitation, began to talk about the distressing experiences during the past years; this was different from how*

*Robert's mother had predicted he would behave. The circumstances at home had improved a great deal, and Robert enjoyed going to school a lot. The parents were trying to focus on giving him structure and making some demands of him, which he seemed to accept very well. Over the past few months, he had tried to gain attention a few times by retching, but this had almost come to a stop. He was now attracting attention in a socially acceptable way.*

Normal responses to loss on a *cultural* level consist of traditional rituals that become apparent in our multicultural society and in healthcare. These may govern farewell ceremonies such as sacraments, cleansing, conjuring evil spirits, the use of incense and other objects. Nowadays, grief responses on a cultural level may be newly modified rituals, being a mixture of traditional rituals and contemporary aspirations.

### **Complicated grief and UBS**

The criterion for recognising complication in loss processing is the *damage-criterion*. When a client causes damage, or threatens to cause damage, to himself or to people around him, there are good grounds to take immediate action. We can speak of complications when the client's life remains dominated by the consequences of their loss with no signs of amelioration, or there may be a continuing lack of response or the response exhibits signs of compulsion. The person might be very depressed, neglect or isolate themselves, or become aggressive or suicidal. An example of extreme complications in mourning happened to the family of a dentist: after having lost a son to cancer, the parents killed their remaining children, then tried (and failed) to take their own lives. What also has sadly happened more frequently lately is that people with complicated grief have isolated themselves after a loss, and have been found dead in their homes several weeks later.

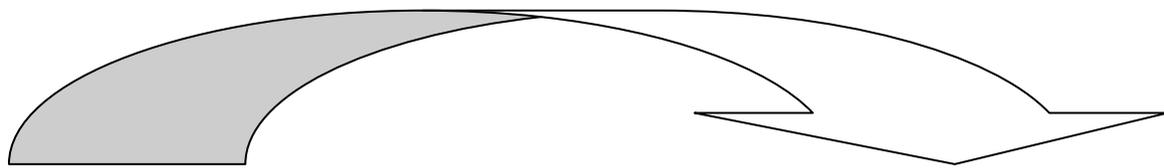
Some homeless people are known to be burdened with unprocessed loss situations: bereavements, as well as divorce, as well as redundancy. People who eventually end up feeling that they having nothing left to lose may commit suicide. The question in cases of complicated grief is whether the care professionals involved are capable of recognising the early signals. A list of indicators of mourning complications can be found in the Appendix.

UBS: Unfinished Business Syndrom

UBS is presented here as a phenomenon whereby old pain maintains various *current unexplained* symptoms. (caused and maintained).

New in UBS is the way it explicitly names the gestalt of unaddressed life-events (1), unexplained complaints (2), trigger-effect (3) and multiplier-effect (4). UBS becomes thereby an explanatory system for a widespread phenomenon, many people are suffering from and often not are helped properly. Early recognition of the *unfinished-business syndrome* could offer perspective to a group of people who for some time have experienced suffering as a result of unexplained symptoms.

#### 4. Multiplier effect



#### 3. Re-activating old pain (UB)

Deterioration  
complaints

1. Unexplained complaints
2. Sensory triggers



#### 2. Trigger effect

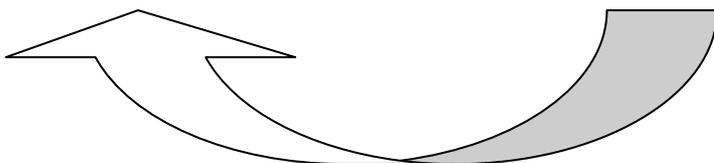


Fig ? The negative UBS spiral with trigger effect and multiplier effect: triggered old pain works as a 'multiplier' for current and existing complaints.

#### The four characteristics of UBS

UBS is the combined presence of four characteristics in the client situation:

1 Current *unexplained complaints* on a bio-psycho-social level, i.e. medical (bio), personal (psycho), relation, family or on employment related level (social);

2 One or more sensory *triggers* causing an increase in complaints/symptoms; triggers are specific sensory stimuli that reactivate old pain from previously unfinished life experiences in the here and now.

3 Previous *unfinished life events* in the client's biography, such as previously unaddressed experiences of loss, unprocessed traumatic experiences, unfinished conflicts and unfinished life periods.

4 Multiplier if complaint maintaining by negative problem *coping* and negative support.

#### Explanation

The unfinished-business syndrome (UBS) is the cohesive phenomenon of the four-abovementioned characteristics. UBS is best described as an interaction between these characteristics. It is important to recognise the client's current complaints/symptoms. Subsequently, the three other characteristics that could potentially maintain the actual complaint are mapped out together with the client. Within the multi-methodical approach, these factors are managed systematically. This occurs using non-directive counselling combined with more directive methods, aimed at breaking the vicious circle of complaints

and their consequences (see Chapter 13) Treatment perspective could appear to be developing when the current unexplained complaints are set against a background of unfinished life experiences.

### **Professional support: the responsibility to create favourable conditions**

*Grieving for a loss can be so sad. But how am I to divide my available time to make room for showing my sympathy? For a terminally ill patient who had just returned from hospital to die at home, the instructions said: 'a 10 minute wash'. Straight after this, I had to hurry on to the next patient for '5 minutes of drops'. After my duties, I decided to go and pay another visit to the first patient. (Professional at the Congress, 'Loss and Mourning in Nursing', November 2001).*

It is the responsibility of health care agencies to create conditions for practising not only according to the medical model of care, but also according to the experiential care model. When there are waiting lists for the first priority – curative care – experiential care is bound to suffer.

No wonder that many professionals complain about the dominance of recovery targets in healthcare, and that grief counselling is categorised as 'palliative care'. A professional described the lack of favourable conditions in this way: 'There's no policy on grief counselling, no directive, no protocol, no clarity as to how much time we are allowed to spend on it'. The core issue for many professionals is the lack of time and lack of understanding in loss and grief-dynamics. Although signs of mourning are recognised, nothing can be done, much to their frustration. This was put into words by another professional:

*You notice the signs, but it usually ends with just that. Just because of insufficient human resources, you are unable to go into it and explore. You hear what is being said but you can't offer any support.*

Policy on time management and human resources to put grief counselling into effect is needed. It is the responsibility of the health agencies to create favourable conditions for both cure and care. In terms of targets: 'a 10 minute wash of a terminally ill patient' should be combined with '30 minutes of griefcounselling'. Healthcare agencies should commit themselves to creating conditions for a first-rate practice of cure and care.

## **Conclusion**

*Nothing is so practical as a good theory. (Kurt Lewin)*

The frequent confrontation with clients and families experiencing a loss justifies, in anticipation of this aspect of professional practice, a systematic and structured preparation of professionals during training. The professional will then feel properly qualified to support clients who are wrestling with life's agonies and to cope with distress in their professional practice. Learning how to address the client's emotions as well as their own, means that the professional is unlikely to victimise the client who experiences a loss, and is able to support them with compassion.

## APPENDIX – Guide for casemanagement in griefcounselling

Professional supporting the client in care (e.g. within primary care agencies, work related organisations, schools, etc.)	Symptoms (in behaviour) of the client/patient/resident/ employee/etc.	Interventions helping with grief
<b>PSYCHOSOCIAL CARE</b>		
I. Physician		Doctors/nurses/teachers/ physical therapists/managers/ personnel officers
1. Signalling grief	Hypothesis: direct or indirect attention-seeking behaviour related to loss	Observe Record behaviour Identify intervention needed
2. Grief counselling	Test hypothesis: is there any evidence of a link between the complaints and a loss?	Anamnestic grief counselling by primary care professional: the story of the loss
3. Grief screening	Identify: <ul style="list-style-type: none"> <li>• Loss related complaints</li> <li>• Risk factors</li> <li>• Complications</li> <li>• Available time – is it sufficient?</li> </ul>	Is there evidence to suggest the need for more intensive care? (Go to 4.) If screening shows complications or contra-indicators, prepare referral (Go to 6.)
4. Preparing a transfer to grief counselling	<ul style="list-style-type: none"> <li>• Client’s acknowledgement of their need for help</li> <li>• Attributed need for help</li> </ul>	Make proposal: e.g. ‘You need/are entitled to more care. I recommend social work. Consent (Go to 5.)
<b>PSYCHOSOCIAL COUNSELLING</b>		
II. Social worker		Social work
5. Multimethod social work practice Indepth grief counseling	<ul style="list-style-type: none"> <li>• Coexisting problems</li> <li>• Normal/complex/uncomplicated grief responses</li> </ul>	Differential diagnosis De-stressing and empowerment interventions In case of contra-indicators (e.g. complicating factors following screening), prepare referral (Go to 6.)
III. Specialist care (e.g. by traumatologist, psychologist,psychiatrist, mental health agency)		Grief therapists, debt advisors, pastors, creative therapists
6. Grief therapy and other specialisms (complex addiction, housing, financial, couple, family stress)	<ul style="list-style-type: none"> <li>• Complicated, interrupted loss processing according to the damage criterion</li> <li>• Other specific complaints</li> </ul>	Specialists in grief counselling and other specialisms (in addiction/housing/financial/couple therapy/family therapy)
IV. Self-care: who is taking care of the carers?		All professionals mentioned above
7. Self-care for professionals working with grieving clients	Emotions-based work-stress of professionals themselves – being emotional, feeling distressed/upset	Support by colleagues, reducing the strain; possible assistance from within the organisation

## Notes

### STEP 1: Signalling grief

The term signalling grief can be understood as follows: systematically recognising the correlation between the client's (or other's) perceived attention-seeking behaviour and a sustained loss. There could be a recent change in the client's behaviour, showing a direct or indirect need of some attention to be given to their mourning. The client (or spouse, for example) asking for some attention for the loss in a direct way may ask questions like: 'Can you spare me a moment, please, because something has happened to me?' or 'I can't handle this alone; could you help me, please?' Asking for the professional's attention for the grief in a more indirect way could be done by drawing attention to something else indirectly related to the grieving, rather than to the loss itself.

### *The withdrawn or difficult client*

Signalling loss generally is an inextricable part of care. For good care should automatically be about signalling all sorts of cries for help, loss included. However, the need for griefcounselling in coming to terms with a loss is not always recognised, as the specific signals are often overlooked, resulting in the client not getting the attention they deserve.

### STEP 2: Grief counselling

Grief counselling is a form of individual, client-centred, one-way care. The aim of grief counselling is to give the client the opportunity to tell the story of their loss and, through this, to find proof that the expressed complaints are linked to this loss. Grief counselling is a form of experiential care for the client and their family, which provides tools for the professional to identify the client's areas of loss that need attention (e.g. the fear of bad news; the feelings of depression). The professional makes use of a suitable mix of counselling techniques, allowing the client optimal space.

### STEP 3: Grief screening<sup>2</sup>

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<sup>2</sup> The term 'screening' generally stands for detailed investigation (Roos, 2001). Diagnostically speaking, screening is a form of epidemiology of large groups of people used, for instance, to gain insight into the extent and gravity of phenomena such as breast cancer and sexual abuse. Here, the term is also being used as a synonym for a regular diagnostic examination.

Grief screening is about assessing the client's need for extra support to cope with their loss, and whether any additional specialist focus on their loss is indicated (e.g. from the nurse, the general practitioner, the social worker, the vicar, the psychologist). This may result in a referral.

#### STEP 4: Preparing a transfer to grief counselling

Here, we are talking about the client's prepared transfer to a colleague in the same or another profession. The phrase 'preparing a transfer' is preferable to 'referral' in relation to the process and nature of the counselling intervention. In broaching this with the client, the following form of words could be used: 'You deserve to be seen by my colleague. What would you say if I ask you to come and visit him/her?' Social work with multimethod competence is indicated when the client has normal stressreactions to a complex and impressive life-situation. Specialists are indicated if the client has complicated reactions.

#### STEP 5: Multimethod social work practice

This implies social work treatment of the client's sticking points or blocks in coming to terms with his loss. Often in grief there is a lot of strain resulting in the client having stress-related complaints. Indications to call in a social worker are: a particular source of stress requiring some additional social care; and a diversity of stress sources, such as a plurality of losses (multi-loss situations), entwined grieving (as a result of both a loss and a trauma), cumulative problems (a recent loss on top of previous losses) and multi-problem situations (having to come to terms with a loss as well as housing problems and child raising issues, etcetera.; any other complex problems which do not result in complications.

The social worker makes a list of areas to be addressed, and their exact nature and difficulties. They systematically and methodically attend to all occurring points of distress (e.g. 'It's not entirely clear to me what the doctor told me,' 'I don't see any way out. What in my life is worth living for?'). The targets of the social work interventions are stress-reduction and greater stability – individually, in communication, and socially – until the client has calmed down and can go on, under their own power. By carrying out the screening, the social worker can also ascertain any possible complications. If so, preparation of the transfer to specialist care is indicated.

#### STEP 6: Grief therapy and other specialist approaches

The term 'grief therapy' refers to specialist treatment of mourning with complications by an accredited psychologist, psychotherapist, psychiatrist or mental hospital. When the client is

likely to put themselves or their relationships at risk – by self-neglect and self-mutilation, suicide intent and attempts, threatening or showing aggression – then grief therapy is called for.

In case of specific difficulties, other specialist treatment can be called for (e.g. a pastor for spiritual problems; debt advisors in the case of complicated money problems; a creative therapist for problems expressing emotions; a psycho-motor therapist in case of problems with motion; and a case manager in the event of logistical problems arising from the involvement of multiple care agencies and services on a single case.

#### STEP 7: Self-care for professionals working with grieving clients

The term 'self-care' is about care for all the professionals involved (e.g. nurses, general practitioners, social workers, pastors, grief therapists, child therapists and others) in supporting each other as colleagues. The premise is that caring for grieving clients is likely also to impact on the professionals themselves. Alleviating the strain of the compassionate work will prolong their commitment and good health.

Besides the support of the head of department or immediate colleagues, self-care may consist of co-counselling between colleagues so that accumulation of stress/distress can be prevented – for example, in a weekly 60-minute session, two colleagues may take turns to listen to each other for 30 minutes each. Counselling between colleagues is a pre-emptive measure to avoid burn-out. Establishing a team of colleagues to be on stand by in case of more severe incidents can be very beneficial, too.

Ineffective management of long-lasting, medium stress (e.g. organisational problems, strained relations between team members) or high stress (e.g. death of a team member) situations eventually may lead to stress accumulation. This may result in overload and even in burn-out. With ineffective management of acute, extreme stress situations (e.g. client assault or other traumatic incidents), there is the risk of trauma complications (such as Post-Traumatic Stress Syndrome). Self-care is a shared responsibility of the individual worker, colleagues, heads of departments and management.

#### Reference

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