



Living loss:
a helping hand

**Living loss
is like unrequited
love**

 **cmt&vm**



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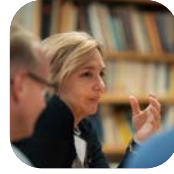
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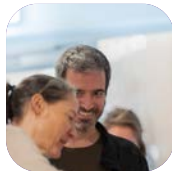
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What is Living Loss?

The theory according to Wikipedia

According to Wikipedia, 'living loss' or 'chronic sorrow' is a chronic form of grief in response to a permanent life-changing experience. It is distinguished from other forms of grief by the constant presence of sadness.

Living loss mainly occurs in people with, or the relatives of those with, a disability, addiction, a chronic illness or mental disorder.

The Dutch term was coined in 2017 by the Belgian clinical psychologist Manu Keirse.

A close-up photograph of a woman with long, wavy blonde hair and a young girl with long blonde hair. They are both smiling and looking down at a small, fluffy black and white dog that they are holding together. The woman is wearing a blue denim jacket, and the girl is wearing a light-colored sweatshirt. The background is softly blurred, suggesting an indoor setting.

*Everything, or a large
part of your life, will
be different to what you
expected or planned.*

Definition and characteristics of living loss

The term 'chronic sorrow' was first described in 1962 by Simon Olshansky who was researching the feelings of parents of children with disabilities. In 1998, the theory of chronic sorrow was developed by Georgene Gaskill Eakes, Mary Lermann Burke, and Margaret A. Hainsworth. They defined it as: "the presence of pervasive feelings related to grief that have been found to occur periodically throughout the lives of individuals with chronic health conditions, their caregivers, and family." The theory says that living loss is a normal response to experiencing a loss and can be supported through the use of positive coping strategies. According to clinical psychologist Manu Keirse, living loss is a loss that never goes away, that continues in its progression, and can be compared to the process of grieving. In contrast to grief after a death, where the intensity of the grief often decreases over time, with living loss the intensity of the grief can increase. With living loss, the person and their loved ones are repeatedly confronted with limitations and must constantly adjust their vision of the future. Living loss is not a diagnosis and should not be confused with Prolonged Grief Disorder, which

is listed in the DSM-5 (Diagnostic and Statistical Manual of Mental Disorders). The Manual is a classification system in which international agreements have been made about which criteria apply to a certain mental disorder based on (new) scientific insights. It is emphatically not a diagnostic manual. A diagnosis is made by means of extensive and accurate psychiatric examination (according to the applicable guidelines), as it refers to a form of complex grief that occurs after a death.

(Source: Wikipedia)

That was the theory covered, but... what does this actually mean?

The term living loss is not necessarily the right term, as experienced by people who are dealing with it. Some find it an appropriate term, others do not, but we have no other name for it. For the time being, and for lack of a better term, we use the term living loss in this guide, with the caveat that it can have a different meaning and depth for each person involved.

Causes and triggers

Suppose you are expecting a baby. Everything seems to be going well. The pregnancy was wanted and you are excited, despite all the discomforts of pregnancy, for the birth of

your child. However, at the 20-week ultrasound it turns out that something is very wrong with your little one...

Suppose, after a normal pregnancy where everything went perfectly, the delivery doesn't go as planned...

You get it. If your life changes drastically and the future of your child(ren), your relationship, or your family situation suddenly or gradually becomes unsettled, then that can be a reason for living loss. Everything in (or a large part of) your life will go differently than you thought or planned.

The images that you had in your head no longer fit the current situation.

The big picture and/or the smallest details of your life can and will be

different to what you thought. This requires constant adjustment. Over time, you can be confronted with situations that you never thought you would experience, and everything in your heart and all the dreams you have, turn out very differently.

An example:

Your oldest child has a developmental delay. They will never be able to walk, but can still crawl. After two years you have a second child, who quickly surpasses your oldest child in all kinds of milestones and developmental stages. Your second child goes to school, walks, runs, talks and learns quickly. How you wanted your oldest child to have experienced such a development and with every step

Suppose, after a normal pregnancy where everything went perfectly, the delivery doesn't go as planned...

Suppose your child has an accident or illness at a young age, which will leave them disabled for the rest of their life...

Just imagine, ...

your youngest takes, you are confronted with the fact that your oldest child will never be able to achieve the same. No matter how old they both get. This ranges from cutting and pasting, to sports, to having a partner, to finding a job and so on. You are constantly invited to view and assess the development of your oldest child differently.

Another example:

Your child turns out to have a skin condition at birth that will mark their body for the rest of their life. From day one, people stare at your child, or are scared, or abruptly turn to face the other way. Every look – even if someone only looks casually, as they would look at any other person – feels to you as a parent as judgment, disapproval or rejection of a person you very much love. That feeling does not go away easily and you and your child will continue to see and feel those looks. You begin to arm yourself emotionally against it and attempt to guide your child as best you can in dealing with these situations. That is called developing a ‘coping’ strategy, which we will discuss later. Your child’s proud ability to ‘show off’ thus unintentionally takes on a different meaning.

The point we are trying to get across is that living loss can manifest itself in all kinds of ways.

The Difference Between Living Loss and Other Forms of Grief

Living loss is actually a ‘strange thing’, because it refers to something that will not be, something that will not come to be or something that will not ever happen. In any case, it’s about something in the future that you can already feel sadness about. This is in contrast to, for example, grief after a death, or the loss of a physical function, a relationship or a job. Something that has been and that you are missing, something that has been completed and that is behind you. As grief-loss therapist and educational psychologist Tanja van Roosmalen puts it: with living loss there is never a full stop, but always a comma... In other words, there is always another situation in which living loss raises its head.

Sadness

The word sadness has been mentioned a few times. Perhaps some further explanation about this is needed. Within psychology, there are different forms of sadness to be defined. We will discuss them briefly



here and perhaps you might even recognize yourself in one of them...

Absent sadness

In this situation the person tends to block out their feelings. This person will act as if nothing is wrong or nothing happened. If the subject is discussed, this person will pay just as much attention to it as to any other subject. What then happens is that someone uses denial as a coping mechanism, something we do (un)consciously with our mind or emotions to deal with or to avoid a problem or stress. The person sees

the problem or stress as so great that they can't face it, and so they concern themselves with other aspects of life instead. However, sadness cannot be suppressed, but will always somehow expose itself - even if it is through fear, physical complaints or by having less overall patience.

Anticipatory sadness

If you know that a loss is imminent, but this loss has not yet occurred, you may experience anticipatory grief. For example, think of an impending divorce. Or when, in ad-

dition to the visible skin condition, major neurological complications are expected. The loss has not yet occurred, and the feeling of sadness/loss/mourning alternates with a need for closeness to this person.

Chronic sadness

We speak of chronic grief when someone fails to process loss. With chronic grief it seems that someone refuses to accept the situation. In some cases, you see a strong focus on keeping the memories of the person or situation that was lost alive. In extreme cases, someone's life becomes more and more paralyzed and the continuous pain is the only constant.

Inhibited sadness

Not everyone expresses emotions or words with the same ease. With inhibited grief, people who have more difficulty communicating have an extra challenge. This is something you often see with children, but also with parents who try to stay strong so as not to influence their children. (However, children often know exactly when something is wrong with a parent.) Here too, it applies: grief cannot be pushed away...

Unauthorized grief

Sometimes grief is rejected by the environment or the people around it. These people will try to drown out the pain.



Often from a confrontation with their own values and standards. For example: 'You can be happy that you had a healthy baby, it is only a spot on the skin.'

Delayed Grief

If someone initially wants to ignore the pain, it can happen that the sadness returns after a while and comes back even stronger. This can take years and can be triggered by something very small and seemingly insignificant. We often see that this is accompanied by various physical and/or emotional complications.



*You can be happy
that you have had a
healthy baby, it is just
a mark on the skin.*

The Impact on the Family

A lot of information has been written about living loss and how it impacts people, relationships and family structures. People who work in bereavement care have often shared their expertise on this subject. Below you will find a section of the guide for parents after the diagnosis, which was written about at an earlier stage and specifically addresses living loss.

Gain and loss

Gain

'A special child. And that's it.' A child with a physical and/or mental disability or a chronic illness is a special

child. Special, because they require more intensive care but also special because you can enjoy more of the small moments and milestones. Even more than with children without a disability. And of course, you are also proud of what your child can do. And grateful for the loving, endearing moments in contact with your child. Your child can also have a positive effect on the development of your family and yourself. In this way, your child can contribute to cohesion in the family and you are challenged by the situation to be more inventive, empathetic, resilient, and better at putting things into perspective. You could call that the 'gain' of having a child in need of extra care.



In addition, there is also loss

Maybe you don't think about it as much. Because it is always better to look at the glass as half full rather than half empty. It is better to look at the possibilities than at the impossibilities. Both are true. And yet it is also the reality that there is a different perspective for your child, different social acceptance, different possibilities to lead a 'normal' life. And for yourself: a child with a disability or chronic illness requires time, energy and money. And, perhaps even worse, you might encounter a lack of understanding from health insurers, care providers, teachers and other professionals. That is extremely frustrating. Your child also requires you to adjust your own expectations about family, work, free time, and relationships with your partner and friends. With a special child you lose a sense of carefreeness.

Coping with loss

Two types of loss

Every parent develops their own way or style of dealing with a child who has a visible skin condition or other condition (e.g. neurological). One

person may develop a problem-solving style while another can develop a more emotional style. These styles are not right or wrong. It can help to have insight into your own style and that of your partner. This will give you a better understanding of each other and you may be able to adopt and understand certain elements of the other person's style.

Problem-solving style

If you adopt this style, you look for opportunities to resume normal life. This requires you to adapt to the extra care your child needs. It involves adjustments within yourself: changing your dreams, being available for your child with both time and money, not being afraid to confront care providers, and also: mobilizing a network of care providers (professional or otherwise), dividing tasks between you and your partner, keeping away from parents or friends who offer unsolicited advice.

Emotional style

If you adopt this style, you feel your living loss. For example: by feeling the loss of time and money, of carefreeness, of perspective. To recognise and admit your feelings of loss with both painful and helpful feelings, thoughts and activities. Allowing your feelings will help you to understand that you love your child unconditionally, to release pent-up anger and make room for the problem-solving style.

The problem-solving style and the emotional style belong together. One time you are more focused on arranging and caring, while another time you are 'losing the plot'. Then you feel down or frustrated by, for example, the conditions of the health insurance company. As long as both styles alternate, things are fine. However, if only one style dominates, the danger of a burn-out or depression lurks.

Discover your loss style

To discover which loss style you tend towards, two questionnaires have been developed. It is advisable to fill in both questionnaires, so that it will help to clarify which style suits you best; at this moment. It is a snapshot, and at another point in time this can certainly be quite different.

For each question, note to what extent the answer applies to you and the corresponding number of points. Then add up all the points and read the result to see what your score means.

Rarely or never = 1 point
Sometimes = 2 points
Often = 3 points
Very often = 4 points

There are no right or wrong answers, it's all about how you're feeling!



Emotional Style Questionnaire

Now that I know that my child will need lifelong care:

- I don't recognise my feelings about the loss of carefreeness
- I find it difficult to accept my child's disability/illness
- I feel a strong desire to have a child without a disability/illness
- Is it difficult to make extra time for/with my child?
- Am I sad that my child doesn't have a 'normal' perspective?
- Am I increasingly locking myself up at home?
- I feel passive and unable to provide additional care
- Do I think life with my child is difficult?
- I avoid thinking about the future
- Do I often feel left out within the family?
- Do I feel different because I have this child?
- I am looking for friends with whom I can cry

Problem Solving Style Questionnaire

Now that I know my child will need extra care for the rest of his or her life:

- Do I adjust my lifestyle to my child?
- I think about the perspective of my child
- Do I feel relief knowing my child's diagnosis?
- Am I looking for distraction to avoid feeling the burden of caring for my child?
- I involve as many other people as possible
- I avoid negative feelings about my child
- Do I arrange the best help for my child?
- Do I feel proud of my child?
- Am I going to resolve the conflict with professionals (health insurers, doctors, teachers) and/or not avoid others?
- Do I feel unconditional love for my child?
- I am looking for people who make me feel positive
- Am I always looking for opportunities for my child?

The result

Have you filled out both questionnaires and added up your score? Then read below what the score means.

Emotional Style Questionnaire

Was your score less than 15 points? The problem-solving style suits you better.

If you scored between 15 and 35 points, do the exercise 'Integrating the situation into your life'.

If you score more than 35 points, please read further under 'great sadness'.

Problem Solving Style Questionnaire

Was your score less than 15 points? The emotional style suits you better.

If you scored between 15 and 35 points, explore how you can strengthen your problem-solving style.

If you score more than 35 points (the emphasis is mainly on a great involvement with your child), then a burn-out may be lurking. It is then advisable to take more distance from your care tasks and pay attention to self-care.

Closer to your feelings

It is not always easy to get closer to your feelings and thoughts. You may not allow for them and recognise your underlying feelings. As a parent, you simply feel responsible for your child. But those negative feelings remain, deep down.

Or are your feelings so intense that they completely take over? Do you want to develop a better understanding of your feelings and learn to see/experience your feelings without judgement? Or do you want to distance yourself from your feelings and be able to look at your feelings as a spectator? Then try mindfulness exercises.

Giving direction to your life

The circle of influence can help you avoid, change or accept situations. For example, from the circle of influence you can try to understand why you or your child reacts the way you do. You can talk about it with others.

This helps you avoid, accept or change the situation. Changes can involve calling in help, dividing roles differently or adjusting your own expectations.



*As a parent,
you feel responsible
for your child.*

Not all situations can be avoided or changed. For example, you remain responsible for your child and you can be confronted with the fact that, despite your child needing it, help is not always easily available for you. Perhaps these kinds of stressful situations are an opportunity to evaluate and adjust your expectations and values. This can save a lot of frustration. If you want to further explore the values that guide your life and how you can give meaning to your life with a child who needs extra care, maybe try using value orientation.

You can hold on to changes by searching for a film, music, painting, story or metaphor that gives you the strength to implement the changes. See if you can capture your experiences with stressful situations (reaction, feeling, thinking and values) in your own story, visualization (drawing, painting, image, collage etc.) or music.

De-worrying

'Do you have a problem in your life? No?

Then don't worry.

Do you have a problem in your life? Can you solve it? Yes?

Then don't worry.

Do you have a problem in your life? Can you solve it? No?

Then don't worry.'

(Gaur Gopal Das)

That is a powerful way to engage your positive change energy.

Talking to other parents

Different approaches can help you through this. But perhaps it might help the most to talk about it with other parents who are in a similar situation and/or who are further ahead on the path you are on.

Worrying

Finding solutions and arranging extra care can take up a lot of your time. You keep worrying without it contributing to solutions. Or you take care of things yourself without looking to see if someone else can do it, you're on autopilot. Taking a step back from the situation can give you some space and helps you to look at the situation in a different way. If you want to take more distance from your thoughts and from arranging everything, use de-worrying.

To help you reduce worrying, there are several exercises you could try:



Exercise 1 | Think further or not?

- ♥ Describe the problem you are thinking about with as much detail as possible. Then ask yourself: Is it a concrete situation with a focus towards the now (characteristics, facts and figures)?
- ♥ Are there any identifiable steps towards a solution at this point?
- ♥ Can you create thoughts that lead to action?
- ♥ How are you going to work towards the solution in small steps?

Exercise 2 | Rest from your heart

- ♥ Focus your attention on your heart area, the center of your chest.
- ♥ Keep your full attention on your heart. As you breathe calmly, imagine your breath flowing in and out of your heart region.
- ♥ (Re)experience a positive feeling. This can be a feeling of love for a person, but also appreciation and gratitude for the good things in your life.
- ♥ The more you practice this, the easier it will become to create and truly experience the positive feeling.

Exercise 3 | The power of your imagination

A place of security

♥ Think back to a situation where you felt wonderfully carefree, or a place where you felt completely safe. Can't recall anything? Then imagine such a place or situation. Try to think about as much detail as possible and create an image of what it is like there.



Preventing stressful situations

You can prevent stressful situations by 'taking the bull by the horns' and looking for the positive in your life. Everyone will praise you for that. But such a positive approach does not always work. Fear and uncertainty can keep you from doing so. In order to be able to endure difficult situations, it can help to curb overly intense reactions, even if only for a short while. If you want to temper overly intense reactions, try using avoidance options (see 'avoidance actions' in this document).

Giving meaning

You are used to organising, taking

control and keeping a grip on the situation around your child. But your child and perhaps also your environment can suddenly confront you with the unexpected and the unpredictable. You can get angry about that and start trying to gain maximum control again. But you can also look at the way in which you deal with vulnerability. In fact, it is always about being able to deal with taking control on the one hand and leaving it to someone else on the other. The balance of keeping control on the one hand and allowing vulnerability on the other. Powerful building blocks for your problem-solving ability are your values. If you want to

Exercise 4 | Slowing down

♥ Where possible, perform daily activities at a slower pace with your full attention and involve all your senses. Do not rush, but complete the activities with care and attention. Without commenting on it further in your head, criticizing, judging or whatever. Are you in the shower? Make the movements slower and be aware of what you feel, smell, hear and experience. Your thoughts are still there, but you can leave them in the background

explore which values you have that will give direction to your life and how you can give meaning to a life with a child with extra care, use value orientation (see 'value orientation' in this document).

Great sadness

Does the outcome of the test show that you experience the living loss of, for example, a carefree upbringing as a great sorrow? That does not necessarily have to be a bad thing, but it can lead to you giving up easily, passivity, sensitivity to your environment, tension within your family and perhaps even (in the worst case) depression. Vulnerability plays

an important role in depression. For example, it can be about your concern about raising your child without worries, about losing your dreams for your child, about your concern that your freedom is permanently restricted, about your concern about the negative influence that your child may have on the relationship with your partner. Parenting a child with a mental and/or physical disability or chronic illness can lead to mood disorders. Especially if social support decreases or if you experience social rejection and isolation.

Questions that may help you

What feelings keep triggering your sadness?

Can you distance yourself from your feelings and enjoy the here-and-now moment more?

If that doesn't work, then it may be a case of depression. You can further investigate this by answering the questions below under 'mood meter' in the next chapter.

Mood meter

Answer the questions below with:

- Not at all
- A little bit
- Neutral
- Quite often
- All the time

- I feel sad most of the day

- I cry easily

- I find it hard to be engaged and interested in something

- I have thoughts of suicide

- I hardly have any energy for anything

- I worry a lot

- I can't shake off gloomy or bad thoughts

- I don't have fun anymore

- I blame myself for all kinds of things

- I feel worthless

- I see the future as bleak

- I have less appetite than before

- I sleep badly

- I have difficulty concentrating

- I have difficulty making decisions

If you answer several questions with 'Quite often' or 'All the time' and your depressed mood has lasted for more than two weeks, it is advised that you seek some professional help.

*There are no
right or wrong
answers, it is about
your feelings!*



Values orientation

Some situations just can't be changed. This means you remain responsible for your child. You can run away from them, you can try to change the environment, but you have to tackle a large part yourself. This can cause stress. For example, you are confronted with the imperfection of life while you are so keen on perfection. You can be attached to the controllable while your child confronts you with the vulnerable. Your situation can be an invitation to look at your beliefs again.

We have already provided a guideline for this in the de-worrying exercises. For example, it involves changing the limiting belief that 'the life of a child in need of care is a limitation for my career' to the stim-

ulating belief that 'the life of a child in need of care moves and changes my career'. Underneath our beliefs lie our values and the way in which we want to be of significance. Values are our powerful motivators.

Your child invites you, as it were, to search for a new meaning to give to your life. As crazy as it sounds, you can draw inspiration and strength from your living loss. It can make your life worth living. Values are like a lighthouse or a compass that show you the way and help you make choices about how you want to live your life.



'How do I want to be remembered later?'

To get closer to those values, you can ask the question 'How do I want to be remembered later?' For example:

"I would like to be remembered as someone who..."

♥
... was social and always there for others".

♥
...was strong and knew how to run the whole family".

♥
...had the best intentions for his child".

♥
...also joined the fight against the disease".

♥
...was loved by children and others".

Perhaps you have already dealt with these life questions (or, as spiritual caregivers call them: slow questions). Because after a profound living loss, these questions arise almost automatically.

You become more aware than usual of your vulnerability and of conscious choices that you can make.

Self-care

Have you focused your attention mainly on your care task? That doesn't have to be bad, but it can lead to overload, going beyond your boundaries, closing off your feelings, not being able to cope anymore, tensions between you and your family members or the care providers and perhaps, in the worst case, to a burn-out.

Burnout

Burnout is seen as an exhaustion reaction of body and mind as a result of work or care stress. People with burnout often describe it as the battery running out, constantly being in too high a gear or stretching an elastic band until it snaps.

To prevent burnout, as a parent you need to find a balance between 'distance' and 'closeness'. Distance so that you are not completely absorbed by the extra care, and closeness to give your child the warmth it needs. The balance between distance and closeness is not self-evident. Sometimes it is scary to let yourself be taken along in the extra physical and emotional care that your child needs and for that reason you have (unconsciously) chosen for distance. Or you merge, as it were, with the care for your child and are sucked into the help that is necessary. You (unconsciously) give up the attention for yourself for the care of your child. In the spectrum

between distance and closeness you encounter two types of parent at the extreme ends: the distant and the overly concerned parent.

The distant parent

The distant parent is reserved, withdrawn, and sometimes trivializes the necessary physical and emotional care that the child needs from the parent. The distant parent keeps their distance by relativizing their own caregiving role and criticizing the role of regular health care. With a distant parent, the child is often the victim.

The overly concerned parent

The overly concerned parent is afraid that the child is lacking and finds it difficult to delegate the care to someone else. After all, the child would be worse off. The overly concerned parent identifies with the care role and simultaneously feels like a victim of the care situation.

How do you feel about that . . . ?

In which of the two types (distant or overly concerned parent) do you recognize yourself?

(e.g. happiness, anger, guilt)

What do you think about that . . . ?
(e.g. it is best to leave care to professionals, I need autonomy, work is important to me).

Distance and proximity

Finding the balance between 'distance' and 'closeness' is important but often also difficult, in part because that balance is influenced by what you received at home from your own parents. For example, if you had warm and involved parents, with whom you could share pleasant and painful feelings, then finding the balance between 'distance' and 'closeness' will be easier. But if you have experienced your parents as distant and uninvolved or as protective and oppressive, then it is much more difficult to find a good balance. You could say that distant parents have stimulated the desire to 'do it yourself' (autonomy) while protective parents unconsciously stimulated feelings of 'dependency'.

Balance

If you choose to bring 'distance' and 'closeness' into greater balance, it may help to think about the following questions:

- How did I experience my upbringing?
- How does my own parenting influence the care for my child? (Balance between 'distance' and 'closeness')
- What would I have liked to have been different in my upbringing?
- What feelings does my upbringing evoke in me? (e.g. fear, resignation, helplessness)
- What thoughts come to mind when I think about my upbringing? (e.g. I would have liked to have parents who . . . , I will have to figure it out for myself to . . .)
- What would I have liked to be different?
- What do the previous questions mean for my care role?



Writing a letter to your parents

For example, the questions will bring you to an unfulfilled wish as a child to be recognized, seen and heard or to be let go and be allowed to be yourself. If you choose the best for your child (balance between distance and closeness), then allowing and accepting the sometimes-painful feelings about your own upbringing is important. You detach yourself, as it were, from the feelings and thoughts that you received from your parents and thus choose a different balance between distance and closeness. To stimulate that process, you can write a letter to your parents in which you openly tell what you are happy about and what you missed. You may not be able or want to send the letter to your parents anymore. Then ask yourself these questions.

How would/did your parents react to that?

What do you need to find peace in what you were taught in your own upbringing?

Helpful and undermining beliefs

Thoughts reflect your beliefs.

For example, the belief:

- My child's life limits my career development.
- My child is a burden to others.
- I know best what my child needs.
- I'll have to figure it out for myself.
- Doctors don't know what my child has, so we don't get good care.
- This is a rare condition, which means I am on my own and my child is not getting the care he or she needs.

The beliefs mentioned are undermining and can be changed into empowering beliefs such as:

- My child's life moves me and gives a different twist to my career.
- Friends are happy to listen to me, especially if I take their schedules into account.
- My grief about our child also touches others in their grief. That feels connecting.
- Others want to help me, but I have to be open to it.

Expressing thoughts

Keep track of your thoughts, for example in a journal. Read the thoughts out loud and start with 'I have the thought that . . . ' Read the thoughts again and do it in a different way.

For example:

Speak the thoughts slowly. Use a different voice. Make a song out of your thoughts. Speak the thoughts as if you were a radio presenter.

What happens? Do the thoughts become less true? Less real? If so, then you create space between you and your thoughts. You can now use your thoughts more for a valuable life with your child.



No 'buts'

This exercise is all about the word but.

A simple word that can have a big impact on your daily life. It tells you that you shouldn't do something, while you actually would like to do it.

The word 'but' keeps you from feeling good.

Instead of the word 'but' you can also use the word 'and'.

For example:

I would like to feel good, but I keep thinking about my child.



I would like to feel good and I keep thinking about my child.

I would like to go to the movies, but I have to pay attention to my child.



I would like to go to the movies and I have to pay attention to my child.

I would like to go on vacation, but I feel guilty about doing so.



I would like to go on vacation and I feel guilty about doing so.

Say goodbye to your 'buts' and change them into 'ands'. Really, it does make a world of difference.

Avoidance actions

Moderating reactions is possible by avoiding situations that upset you. You can do this by avoiding contacts that cause you stress or by seeking distraction.

Contacts that give you stress

For example, when friends say to you: 'You should have those marks removed. This is terrible for your child,' or 'Leave your child to someone else,' while you actually think you know best what your child needs, it is a matter of self-care to ignore those reactions and, in the extreme, to avoid contact with those friends in the future. So take measures to avoid overly strong reactions.

Searching for distraction

Looking for distraction ensures that you are not reminded too much of your loss and your stressful situations. You then do not have to feel your sadness and stress for a while. For example, you can go and play sports or do your hobby.

Anesthesia

Numbing options are aimed at temporarily not feeling your loss or uncertainty about the future. In order to be able to endure your loneliness, fear,

sadness or anger, you can temporarily numb your feelings. Medicines, such as sleeping pills or antidepressants can sometimes provide temporary relief, but should always be used in consultation with a doctor.

Drinking alcohol or emptying the fridge may also seem to numb, but know that this form of avoidance has a negative side effect on your health. It is advisable to consult your doctor if you use these numbing options more often. They can be a signal for something else. Find out which avoidance options you use in certain situations.

Recommendations

The following recommendations may help you:

Don't deny

Don't deny your dark feelings. Don't bottle up your feelings. Talking about your feelings is a relief.

Physical activity

Try to exercise regularly. A short walk or bike ride is often enough. Physical exercise produces a substance in the brain, endorphins, which makes you feel better mentally.

Daily rhythm

Choose regularity and structure in your life, even if you have nothing planned. Going to sleep, getting up and eating at fixed times can help you keep a grip on life. Don't let yourself be led by your own gloom.

Contacts

Keep interacting with other people. You don't have to be ashamed of your sadness. Don't withdraw too much. Others can be a good distraction or support.

Conscious choices

When you decide and consciously choose something, you can regain the feeling that you are in control of your life.



Not perfect

Don't put pressure on yourself to do everything perfectly. This can lead to dissatisfaction, disappointment and compulsion.

Eat healthy

A lack of nutrients can make you feel even more listless and depressed. Therefore, eat a healthy and varied diet.

Outdoor air

Sunlight and fresh air can have a positive effect on your mood.

Relaxation exercises

Relaxation exercises can help you calm your body and mind.

Do fun things

As hard as it is, try to keep doing fun things. Think of things you enjoyed before you got depressed. Pick them up again. You will see that you will feel better afterwards.

Exercise:

Fitting the situation into your life

To explore these situations a little better, you can answer the following questions for the two or three most important stressful situations:

What do I see myself doing in the situation of . . . ? (e.g. running away, snapping, withdrawing)

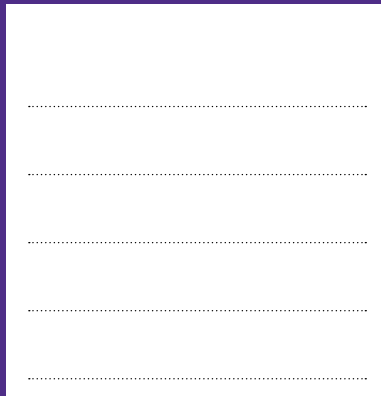
What do I feel about the situation of . . . ? (e.g. anger, fear)

What do I think about the situation of . . . ? (e.g. what will it ever become, I no longer have a life of my own)

Which values are affected in the situation of . . . ? (e.g. no recognition, no appreciation, no control over the situation, indifference of others).

1. Your child can't sleep and is constantly crying.
2. You try to connect with your child but you can't.
3. You are visiting and you and your child become uncomfortable from the negative attention.
4. You hear from the doctor that drastic treatment is necessary.
5. Your health insurer does not want to reimburse certain costs.
6. Your partner puts things into perspective and you are solely responsible for care.
7. Your friends let you down.
8. Your work demands more than you can deliver in the situation with your child.

. . . (supplement with your own situations)



What can I do to avoid the stressful situation?

The negative feelings and thoughts indicate the extent to which the situation is sensitive to stress.

Exersice:

Strengthening problem-solving style

The examples below, which you can of course supplement with other situations, will help you investigate empowering situations.

1. You see how openly your child reacts.
2. You see how happy your child is when they come home.
3. You see how professionals take care of your child.
4. You notice how close your family is.
5. You notice how you and your partner are jointly responsible for the extra care.
6. You notice how your friends encourage you.

Fill in with your own situations!

A large white rectangular area with a purple border, containing ten horizontal dotted lines for writing.

Exercise:

Which situations give you strength?

Which situations give you strength/positive energy?

To explore these situations a little better, you can answer the following questions for the two or three most important power situations:

What can I do to maintain the positive energy?

The positive feelings, thoughts and values show to what extent you derive strength from such a situation. You can hold on to the positive energy by looking for a film, music, painting, story or metaphor in which you recognize yourself and from which you derive strength.

What do I see myself doing in the situation of . . . ?

(e.g. smiling, hugging, talking)

What do I feel about the situation of . . . ? (e.g. joy, tenderness, connectedness)

What do I think about the situation of . . . ? (e.g. what great professionals they are, what a wonderful child I have, what a great family we have)

What values are affected by the situation of . . . ? (e.g. recognition, appreciation, making the best of it together, giving unconditional love).



*Making the best of
it together, giving
unconditional love.*

Support

Of course, professional support is an option and is widely available. Many parents already have contact with a psychologist. Perhaps less well-known is the added value of a grief/loss counselor or spiritual leader. In a number of cases, parents are referred to these professionals for help.

And perhaps you already have a referral, but you do want it for yourself, or do not feel ready to be confronted with living loss. Grief/loss counselors then experience that as professionals they are not allowed to do anything yet. That parents often hold off on appointments and treatment, perhaps to keep

themselves going. The question that professionals then ask themselves is: how do you reach these people, how do you make it clear to them that they can also get started working on this part of themselves?

This mainly concerns families who are seen in the hospital, because they do their best to keep all the balls in the air. Doctors see that support would be beneficial and want to offer help, but the parents are skeptical.

It will take some time to get to a time of peace and that is when questions will arise such as: What now? What will my life look like in the future? What choices have



I made and what choices am I allowed to make now? Am I allowed to think about myself again, now that a large part of the care for my child is taken care of? When there is peace in the family, there will also be more room for questions such as: What now? This can also have to do with energy levels. Previously, there was no energy to tackle things and 'now' there is space to.


The survival of a parent in a situation with a child with special needs goes on and on and parents have to deal with this. Women often react differently to this than men. Some also do not recognize the grief in this situation of living loss due to the constant survival mode. In that

period, all sorts of things are on the 'have to' list: making agreements, dealing with obstructive professionals, organising, fighting and so on.

Sometimes a gateway to the living loss process are the practical things, the small steps, that create space for the loss/mourning part. A child who leaves home for a few hours, for example.

This can create trust that other matters can also be dealt with.

It can provide space to gain clarity that it is actually a 'normal process' when having a child who requires more care and that it offers time to also think about yourself as a parent. You can work from the emotion



This can help build confidence that can be used in other areas.

and get started with that, towards creating space to be able to realise practical matters, while you can also work the other way around; by realising practical matters, thus creating space to get started emotionally. At the moment that diagnostics and treatment discussions are taking place in a hospital, it is not the time and apparently not the place to ask: how are you now? Only when you are 'thrown' back into your own life can space arise to think about questions of meaning and living loss.

There is also almost always a living loss in the partnership relationship, despite the fact that it is rarely or never mentioned. That is already

the case in a 'normal' situation, when a child is born, but even more so when you also have to deal with grief, in the broadest sense of the word. You become a different partner in the relationship and there is hardly any discussion about that. The conversation is often centered around the child and any other children, and when the subject of the partnership relationship is addressed people find that confronting but helpful.

Solidified living loss

Is there such a thing as frozen living loss – parallel to frozen permanent loss? Yes, for example because parents have been in survival mode for so many years and have to deal



with ongoing living loss. Physically, there is a lot of pain in the body. Sometimes the body feels as if there is a hard shell around it, through which nothing is allowed to come. Gradually, through bodywork (see below), and awareness someone can learn how to deal with the causes of pain. Talking can be helpful so that you don't have to feel. An opposite reaction is also possible, that people physically tense up so much that they can no longer find the words. A walking coach can also be effective: outside, in movement, while the attention is not directly on the person.

If you are in your own head a lot, it helps to have it explained to you,

what is happening and what the consequences are, and what the 'coping' strategies are.



What now?


Of course, I cannot look deep into your heart and mind. I do not know how you personally experience living loss, or what role it plays in your life and how you deal with it. Nevertheless, I hope that with this booklet you have gained some insights into what living loss is, how it can manifest itself and what impact it can have on someone's life. Do not ever be afraid to ask for help, or to talk it over, if living loss has a disruptive impact on your life. You are allowed to grieve in your own way, because no one knows better how it feels than you.

Kind regards,
Johannes Verheijden

Johannes Verheijden (1965) is married and the father of three children. Johannes lives in Zeewolde, in the Netherlands. His hobbies include work, giving training /lectures, watching movies, reading fantasy books, cycling, walking, writing ('When love hurts so much'), (sometimes) playing/composing Irish folk music and (more often) being lazy. He also enjoys good food, with or without a glass of beer or wine.

Bodywork explanation

Bodywork uses the intelligence of your body to promote your physical, emotional, mental and spiritual well-being. The components are inextricably linked and influence each other according to various bodywork theories.

A young child is shown from the chest up, standing in front of a window. Their eyes are completely covered by a piece of white, translucent fabric that is held in place by their hands. The child is looking out the window with a slight smile. The background is bright and out of focus, suggesting a sunny day outside. The overall mood is one of curiosity and perhaps a bit of apprehension.

*The fear of pain
is often worse than
the pain itself*



Colophon

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