

## Report "I want to live - despite it all"

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Man often claims physical integrity into old age. If this integrity is suddenly endangered, we lose our footing, develop fears, we withdraw from life and the people around us or lose our self-worth. Feeling helpless and being dependent on others make it more difficult for us to handle our situation and our environment. It is only too gladly that we repress the disease and suppress our grief. So how can we shape our life freely and determine the meaning of our life, if we are not able to see any more, if we can no longer pursue our career? All these thoughts are accompanied by a range of different emotions. It seems impossible to find one's way through and feelings of helplessness and exposure may join in and further paralyze. This lecture is to show how an existential life became possible despite my visual impairment. I do not want to show how people can be accompanied in such a crisis. Rather, I want to show how I as an affected person have experienced this process and how existential analysis has helped me to once again find my will for a meaningful life.

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### Calamity

With the topic of "meaning" we get right to the roots of human existence. Asking for the meaning of life is a characteristic of man - asking why, wherefore, for what reason?

Especially in times of crisis, when we suffer from a severe disease or other calamities, like losing our work place or maybe even losing a loved one, the question of meaning becomes particularly pressing. It is in such moments that we have to find a new orientation in life in order to adapt to our changed reality. Answers on how this can work can be found in Viktor Frankl's logotherapy and existential analysis as a meaning-oriented psychotherapy.

How can life succeed, if something is not working properly any longer? If physical impairments are taking away my freedom to do what I want to do, if I feel insecure in a world with all the things I cannot see, cannot hear or cannot move towards or away from? If life does not work as it used to or if my professional life is endangered, my job opportunities are restricted?

When everything seems to be hard, when the disability or disease is taking its toll on me and my relations or maybe even threatening them? When all I want to do is leave it all behind? When I start doubting my ability to getting a grip on what has happened, when I feel like I am not enough, because there are some things that I just cannot do any more?

These were the questions I asked myself when I was diagnosed with the Stargardt disease in 2002, a hereditary retinopathy that can lead to blindness. Life as I had known it, life as I was used to it and in which I knew my way around was threatened. There will come a point in my life when I won't be able to live like this any more. Feelings of numbness, anger, despair, and fear were taking turns. How can my life be meaningful now?

Finding an answer to this question should become a pressing matter for me.

### Escape into performance

Initially I did not spend too much time thinking about the disease. After all, I did have a remaining vision of around 70%, so the threat was not imminent at that moment in time. And I was needed: at the work place, in my relationship, and the blossoming relation with my daughter that had proven difficult after the divorce and a job-related move. As a result I worked very hard. In retrospective, I know this was my way of numbing and suppressing my feelings.

In existential analysis and logotherapy man is not viewed as the result of inner psychological processes or environmental influences, but rather as a being that can face and shape what counts in life: e.g. maintaining independence, self-determination, mobility, and participation in social life.

Frankl talks about the Copernican revolution, when saying that life is asking the question and man shall find the answer (Frankl 2005, 107). But at that time in my life, I did not yet hear that question. On the contrary, I worked even harder - 16 hours a day had become a habit. People were admiring me, the way I was dealing with fate, the way I was facing my situation. However, due to the work-related stress my vision further deteriorated: initially to 60 %, then down to 40%.

At that time I was still driving my car - until the day I almost ran over a police officer who was standing at the side of the road, securing the site of an accident. I was in shock, did not have the courage to continue driving home, and when I eventually did, I drove very, very slowly. I parked the car in the garage, stood in front of it, took the car key off of my key chain and said goodbye. I have not driven a car since and the bicycle became my preferred mode of transportation. I even biked during fall and winter and I had a little trailer, where I could load my shopping. And again, people had the greatest respect for me, for how well I was coping with the changes in my life.

The questions life was directing at me I still did not need to hear, because I had the correct mindset: I wanted to live! This perspective had already defied several situations in my life up to that

point: my divorce, a severe car accident, a spinal operation and a 6-months bed rest. That was the irrepressible will to live a self-determined and free life. I had no other choice, I was convinced of that. But still, I could feel the insecurity and increasing threat.

### **An important encounter**

I became a member of several organisations, among them Pro Retina Germany, a support group for people with retinal degenerative diseases, where I am a member of the work group Psychological Counselling. This is where I met Manfred Knoke during a lecture on the topic How to live an authentic life despite a disability. Manfred had lost his vision due to a retinopathy and had undergone training as a logo therapist and existential analytical counsellor at an institute in Hanover.

His lecture touched me in a way I had never known before. I wanted to learn more and I participated in the weekend seminar How to win optimism – how to let go. This self-awareness seminar marked a turning point in my life. I can well remember the controversy with my own emotions during those three days, emotions I have only known superficially up to that time.

One key scene occurred the first evening when we were sitting outside, drinking beer and I asked Manfred if he minded me smoking. He responded that he did not mind as long as he could sit somewhere else! I hesitated, but he only smiled and said: "Now I have said "no" to you and the beautiful thing is that I have said "yes" to me." These three days changed my life in the long run, because three years later I started my own training at that very same institute in Hanover.

My decision to hold a speech for this year's congress topic "Is there a way, where there is a will?" also routed from the desire to honor Manfred Knoke, who has died last December very suddenly and unexpectedly. During his seminar, during those three days in the Harzer Mountains, I had learned to say goodbye so I could let go. I had already done that before subconsciously, when I quit driving. But it was only through coping with my disease, my grieving and saying goodbye that I was able to accept my fate. Only afterwards was I able to turn towards life.

### **Changing your perspective**

Frankl says you need to become active and start acting in order to discover your possibilities of meaning. But my life to that point was rather characterized by reacting. I reacted to the things that were happening to me with a sense of defiance, thinking: Now more than ever! I ignored and suppressed any feelings of numbness, anger, or despair. And that was quite easy due to my biographical background, where unpleasant matters were never discussed.

In his essay, Manfred Knoke wrote that *our demands push us into the role of victims because our expectations are not delivered. Helping another person by free will and gladly is a wonderful act, but expecting something, maybe even demanding it, means taking something from that helping individual, taking away his freedom to act freely – and this turns the desire to help into a forced situation, causing withdrawal in many people* (see Knoke 2009). In retrospective, the same thing probably happened to me and my relationship.

Frankl emphasized the power that can mobilize meaning in people's lives. He wrote: Who has a meaning in his life, can cope with any fate. And Frankl even found meaning in his life during his time in concentration camps. I quote from his book *Man's Search for Meaning* "Everything can be taken from man in concentration camps but one thing: the last of the human freedoms to choose one's attitude, to choose one's own way in any given situation. And there was one way or the other!" (Frankl 1982, 108). So the question of meaning is reason for hope, protection against despair and motivation to hold on.

The answer to a meaning in my life was my daughter, who was having a difficult time dealing with my diagnosis. I had a value in my life that wanted to be lived (the value of a relationship with my daughter) and it was something that was providing support. But it was only during my training as a logo therapist and my retrospective that came along with it, that I learned what had been carrying me back then.

It was about something very meaningful to me. According to Frankl, man can aspire to values. Aspiring to values that attract him and by fulfilling them, man encounters meaning. In order to live a meaningful life, we need to first define our own reality. Wanting to do something may not be enough – one needs to be able to also push through, otherwise it will just remain an unfulfilled wish. If man faces the truth, he can build an existence rather than an illusion. This reality changes in the course of our lives and especially with a progressively blinding disease.

### **Prerequisites for existence**

Man needs three prerequisites to lead an existential life (Längle, 2008, 29). First we need the prerequisite of sufficient protection, support, reliability, security, and space. Man needs to feel that he can be in the world. Only when this is given can a sense of basic trust develop in order to engage with life. If man cannot make these experiences, a severe insecurity can develop, manifesting as fear. Man needs to be capable of enduring and accepting. Enduring my disease was something I've learned during the course of my training.

The second prerequisite is experiencing an emotional relationship. Only through the relationship can man experience life. Only with affection can life become more tangible. A sensation can arise: "I like to live". If this prerequisite is not given, one can lose vitality and fall into depression. The person feels worthless and weary. In this context, one requires the ability for attention and grieving.

Grieving is hiding one's self-worth inside, as Frankl puts it. At the end of the seminar with Manfred Knoke I said: "I feel that I have only learned how to see through my visual impairment." What I meant was that I was looking closely at what I was still able to see, for example enjoying encounters with other people.

The third prerequisite for an existential life is given when man can be the way he is with a certain sense of originality and uniqueness. If he is not allowed to be himself and to develop a self-worth, feelings of loneliness and abandonment can develop that are especially troubling if man is not at peace with himself, e.g. threatened by blindness but unwilling to show himself with a white cane.

When I arrived to that first seminar, I was surrounded by visually impaired and blind people – it was almost unbearable. I wanted to leave and it was only thanks to the intervention of an acquaintance who was accompanying me that I didn't budge. It is all about human self-acceptance. "I can get on the road with myself and let life happen." It takes the ability to really look and really see.

Aside from being able to just being, liking life, being able to be ourselves, there is yet another prerequisite for a fulfilled life in order to find meaning in our lives. To live life in fullest devotion, man has to view himself in the context with everything he experiences and all of his actions. It has to be worth it to find values and maybe even recognizing a flawed self-worth and working on our own well-being. Human existence is tightly connected with the need to bond that leads to a life filled with encounters, tolerance and respect.

Regarding the fulfillment of purpose via fulfillment of values, Frankl mentions three value categories that are important for all of us – on a general and more fundamental level.

Those are experiential values, creative values, and attitudinal values. Experiential values involve experiencing the world (aesthetic values, love, art, relationships etc.). Frankl talks about man's ability to enjoy. Part of the creative values as the path to fulfillment of purpose is the active shaping of the world (work place, hobbies, leisure time etc.).

Attitudinal values include so-called human maturity values gained through dispute with life (*misery, guilt and death*).

The attitudinal value is identical with the acceptance or the inner approval of life in the aftermath of a calamity. Only when insecurity and grief over a lost value have calmed down and it was possible to let go of that value, can attitudinal values open new possibilities. Man can once again feel the tension between what is and what ought to be.

### Decision to live

Deciding in favor of a value fulfillment, man takes responsibility over his own actions. Meaningful live emerges, when / can decide freely and responsibly.

Thus, my visual impairment has become a part of me. It is not my disease that determines my life, but I am the one shaping my life □ despite my disability (Frankl mentions the defiant power of the human spirit). Life is happening, it is taking place, whether I like it or not. For me, discovering that I could ask for help was liberating.

Frankl once said that despair is suffering without meaning. But every suffering can be meaningful, for instance in the question: Is there a point in enduring all this? And this was the question I asked myself, when I was awaiting a second operation after being diagnosed with thyroid cancer last year. I could think of many beautiful things I wanted to experience, e.g. getting married or graduating from my existential analytical training.

Manfred Knoke said in his seminar that happiness is a conquest award. Surely, many times I wanted to do things but couldn't push through and thus they remained wishful thinking. But what I can do today, and I mean my self-determined and responsible life, I owe to the fact, that I had said goodbye to my sight. Manfred once asked me, if my ability to see made me worthy. Today I know that it doesn't, but that it is rather values I encounter today despite my disability.

With my story I want to encourage you,  
Encourage you to face your realities,  
Encourage you to face your destiny,  
Encourage you to accept your destiny,  
And encourage you to discover new things.

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