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## Families Living with Anticipatory Grief; How Can We Both Understand and Explain?

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Max and his dad arrived first. It took half a year, and then Martin came along with his mother. It appeared that both boys had a progressive neurological condition stemming from their parents both being bearers of a special gene. A review of their heredity revealed that they were fourth cousins. The process in the period preceding the deaths of the children was extremely demanding. The boys moved gradually backwards developmentally. They lost their vision, language, bodily control and developed dementia. Their parents had been sweethearts from their early teenage years. Despite their great love, they now found themselves toxic for one another. Through a difficult but friendly process, they chose to divorce and to take primary responsibility for one child each. Max and Martin died at 10 and 12 years old respectively.

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I am concerned with practice, also in terms of how it is related to research. When families are living in such a complex and demanding lifeworld as Max, Martin and their parents, we need to stretch in all directions and search for the best of all that is available to provide help for those who need it. Understanding people in demanding life situations is a work of interpretation that demands both knowledge and experience. More than anywhere else, I feel here the importance of the not-knowing position (Anderson, 1997) in which my role as therapist is as an artist of conversation, and my competence lies in facilitating dialogue. In a situation characterized by dramatic changes in the lifeworld of the family, I must listen actively both to what is said and what is left unsaid. The conversational space must be kept open enough to encompass difficult questions, those for which there might not be any answers. It must encompass causal explanations that *do* provide answers. It must offer sufficient peace for us to search for meaning, and there must be space enough to accommodate strong emotions. Meeting Max, Martin and their parents, as well as other families living in similar lifeworlds, has strongly influenced my clinical and academic work. Clinical experiences have become issues for research and developmental work and then feed back into my practice.

In my role as an artist of conversation with Max, Martin and their parents, I have found particularly helpful social constructionism's focus on the power of dialogue to open up a multiverse. This has allowed me to perceive family-professional exchanges as encompassing both explanation and understanding. In encounters, our shared search for a multiverse appears liberating because it creates a wide-angle perspective. When we become curious instead of critical about how people engage in one another's reality, we open for the assessment of alternative paths (Anderson, 1997). My understanding of the social constructionist perspective gives me courage, acceptance and belief in the power of dialogue.

## Illness Phenomena: A Meeting of Medical and Phenomenological Perspectives

Illness as a phenomenon encompasses different dimensions of human life, and as a phenomenon, it consists both of narratives and physiological conditions. A lifeworld such as that which Max, Martin and their parents must manage brings with it a need for knowledge and help with medical, psychological and social arenas. The more intricate and complex the condition, the greater the need for thoroughness in finding ways to provide a holistic service. The challenges faced by the family, therefore, also involve ideas not immediately embraced by systemic perspectives. Families do not need either-or, but both: to explain and to understand. In my effort to keep family-professional dialogues open to the multiverse with families like this one, I have found resources in the work of medical philosopher Fredrik Svenaeus (2011) who views these ideas as well-suited to achieving an understanding of the special requirements of lifeworld's altered by serious illness. Being the parent of a dying child can be experienced in terms of existential threat that becomes anchored in the body as physical pain and despair. The threat of the loss of a child can be experienced as an existential crisis in which *being-in-the-world* changes character and becomes *unhomely* in a threatening and chaotic manner. For parents, explanations are sought in which the *chaos story* can be made more understandable and eventually replaced by a *restitution narrative*. Svenaeus also describes a third type of narrative, the *quest narrative*, the path between these two. In this story, parents can redefine the situation from threat to one in which they can find new meaning because the meaning structure of narrative can be opened, unpacked and displayed in new ways (Svenaeus, 2011).

*Mother:* What was so strange was that they didn't find anything wrong, not on the tests, not in the pictures. And then of course you think, there's nothing wrong, it'll probably be fine. But then everything got worse. When the boys finally got the diagnosis, we screamed non-stop for two days. I remember the feeling of waking up but still being caught in the nightmare. It was as though someone ripped the rug out from under my feet, and underneath there wasn't a floor, just a black hole.

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*Therapist:* Yes, that must have been terrible to find out. You got the worst answer you could get to your questions. I think what you experienced is every parent's worst nightmare, only it was really happening, and there was nothing you could do. When you think back, what made you nevertheless begin to move up out of that black hole?

*Mother:* It was hard, because I kind of couldn't see any meaning in doing it. But, at one point I was completely exhausted by being in so much pain, and I realized it couldn't get any worse. That was a turning point in fact. I had gotten the answer I feared the most, but getting an answer was still easier than feeling the fear of getting the same answer.

*Therapist:* Yes, sometimes we really must go to the uttermost limit no matter how painful it is. What made you able to think differently despite such great pain?

*Mother:* I read about anticipatory grief, and then I thought, yes, that's exactly how I feel. There are others who understand, who know how I feel. That helped me to understand why I reacted as I did. I also read about other families and found comfort and help in what they said. But I also felt guilty, then, about my boys. While I'd been more concerned about death than living, they needed me more than ever. It was about more than just me. I began to think more about what I could do so that they could feel as good as possible.

Diagnoses are descriptions and categorizations of symptoms, and they function in part to legitimize treatment and the need for types of help (also see the chapter from Axberg and Pettit in this volume). With a basis in natural scientific research and experience, statements can be made about how a condition will develop, the possibilities for treatment interventions and prognosis. In encounters with people and illness states, there is therefore a logical breach in the statement that diagnoses are not realities. As systemic therapists, we must acknowledge that they also represent ways of being in the world and describe perspectives existing

in and important to the lifeworlds of many people. At the same time, I will always challenge categorizations that over-simplify people or situations, or in which the explanations provided appear limited to cause and treatment, with lifeworld and context relegated to the background. Descriptions of people will always stand in relation to something greater, to the relation between us, to discourses and to the context that frames the situation. As therapists, we must therefore ask ourselves questions about whether these constructions are helpful and related to what the family is seeking help with, or answers to. Max and Martin's mother felt particularly helpless in the search for a diagnosis and reached a turning point when this frustrating process could finally be concluded. She was told that there was no cure and that her children's lives would be short. Hope disappeared, forcing them to construct new boundaries around a lifeworld in which death had become the frame for life. This medical approach, nevertheless, contributed important answers.

It is important to emphasize the special features of diseases in which hope of improvement is absent and diminishing or loss of function is a part of disease development. When death is the frame of life, conversations always have a context in which drama is present to a greater or lesser extent. In parallel with advanced medical treatment, there is a continuous need for help in creating new constructions of how to live, and the creation of meaning will be a dimension of continual significance (Grasaasen, 2020). By expanding the description of the disease with images that embrace a greater unity of the lifeworld, a more caring encounter can be constructed. Michael White (2008) describes traumatic events such as being thrown into a fast-flowing river after which the only thing one can manage is to hold one's head above water. To get the ground under one's feet, one must climb up onto the riverbank. It is only when one can stand safely that it is possible to find the adequate emotional distance to be able to speak about these experiences and achieve meaningful understanding of what has happened. According to Jerome Bruner (2003), it is then our narrative gift that can give us the strength to accord meaning to experience. Lived life is expressed through narratives in which events are pieced together into meaningful stories. When a breach or a turning point occurs, this structure brings a useful

means of embracing complex experiences and renders them understandable. After the impact of the diagnosis, the mother climbed up onto the riverbank to firm ground, from which point meaning construction resulted in the development of a coherent story that, no matter how tragic, could make family life worth living. As their therapist, it became important at this point to maintain the dialogical space and meet this private tsunami with conversations that acknowledged reality. In subsequent conversations, we slowly changed focus from support and comfort to searching for words that, with incremental steps, produced movement and hope for change in the direction of a new way to live everyday life. We highlighted resources both in the mother herself and in the environment that could make daily life manageable. Attention to living in the now helped her identify meaningful experiences to share as a family that simultaneously created memories for future recollection.

*Therapist:* When you talk about how you got through this early time, I think that you must have found enormous power from somewhere. What is this strength of yours, do you think?

*Mother:* I don't know, and it's not every day it works, either. It doesn't take much before I'm standing on the edge of the hole again. I really just want to carry the boys around in my pockets all the time, because I know that they won't get to be adults. I can still get completely overwhelmed with desperation about the fact that they're going to die. But I think there is a strength in knowing I'm the one who can make their lives as good as possible. And that there's nothing else I'd rather use my energies for than doing just that. I want them to have the best, and that means they need me.

*Therapist:* So, your days are unstable, and some days are more difficult than others. At the same time, I think that I hear that you have great awareness of your own feelings and reactions. What makes it possible for you to keep far enough away from the edge that the grief feels manageable?

*Mother:* It might sound strange, but I'm glad that we didn't lose the boys in an accident or something like that. I think it would've been harder. I'm grateful that I have the chance to prepare myself for losing them. Now time feels a little borrowed. I don't want to waste it. It has taken on a unique value that I guard.

*Therapist:* So, being able to prepare yourself for the fact that they will die helps you to live in a way? To value each day?

*Mother:* Yes. I wake up of course always with restlessness in my body, but then I force that away and begin to think about what might be fun to do that day. It doesn't have to be so much, but I try to create precious moments every day. I feel the best those days I manage to do this. Knowing that time is limited helps me to take care of them.

*Therapist:* So, you look for valuable moments that both make the day a good one and that you can take with you further. Can you describe a moment like that?

*Mother:* Yes. We always get up early in the morning because that's when the boys are in the best shape. Today, we sat around the breakfast table even though they only get fed through a tube in their stomachs. I lit candles with a match and then I pretended that it was them who blew it out. Then they got to smell that strange smell. Small things like that.

*Therapist:* That was a small, beautiful story about the small things. Max and Martin are lucky to have such help to fill their days with sensory, meaningful experiences.

*Mother:* I'm not always so active though. Some weekends when we haven't done so much, I'm really pleased just because we've felt good.

A social constructionist, relational approach to grief and death free people from the clutches of individualistic, pathologized versions of grief that insist on a final stage of acceptance. In conversations with parents, I have been inspired by Lorraine Hedgke (2021) and what she calls remembering conversations. Instead of the adage that *the human being is born and dies alone*, Hedtke locates narrative relational perspectives of life as those that are foundational; all of us are born into an interconnected web of other people. Stories about relationships are resources that strengthen and highlight life as a circular narrative, without beginning or end. In re-remembering conversations, narrative conversational practice is used to create active stories about a fellowship that continues after death. Questions that build bridges between the past and the future have the aim of creating narratives that can continue to include the dead child in the lifeworld of the family. The conversations can give strength and power to the parents by calling forth *memories of belonging* instead of *creating distance* to a loved child. Knowing that they are allowed to *not*

*forget* can be the source of peace. Parents can find a way to go on with the dead child *beside them* instead of having to *put it behind them*. Children can continue to warm their parents' hearts by actively being included in meaningful stories and as part of the lived life of the family (Hedgke, 2014).

## Emotions—And the Curse of Dualism

*Mother:* You hold your hands in front of you like a bowl and try to carry water. Regardless of how hard you hold, it always drips through a little bit. So, with each drop, and it's Max and Martin I'm holding, a little more of them drips through every single day. It happens so slowly that it takes a while before I notice they've lost more function, and when I register that now they can't do what they could yesterday, or last week, I get so sad.

There's a saying that grief is the price of love and the cost of being lucky enough to love. In that perspective, grief is part of life as a normal and appropriate adaptive process to life without the loved one. The narratives of parents in anticipatory grief are often saturated with metaphors. They speak about *moving through unknown territory in a journey without a map, filled with unpredictability* towards a death they know will occur. They feel fear and desperation, so much so that they *do not have energy* and *feel drained* (Grasaasen, 2020). Feelings are abstract, and the use of metaphors is an effort to grasp the ungraspable through using more concrete references in a transformation that makes them understandable. Love and grief are not psychological entities hidden in consciousness, but rather ways to behave that are visible on the outside of the person (Grasaasen, 2022). At the same time, existential thoughts about life and death arise, as well as a continuous stream of new questions about how to cope with life.

Even though the methods of natural science have shown their value in describing genetic and biological processes, this value can be correspondingly poor when describing challenges at the psychological and



interpersonal levels. Through the monological or “thing-language” of science, explanatory models have been proposed in which phenomena such as anticipatory grief and love have been defined, diagnosed and explained in terms of numbers and categories. Discourses about grief have been directed traditionally towards the experience of loss, pain and longing. With the help of modernist metaphors, we are told we must *let go*, *get over it* and *move on* (Hedgke, 2021). Harlene Anderson (1997) calls this pathologizing language, or the “language of inadequacy”, one that is usually static and looks for causes with little room for understanding. Anderson uses a similar metaphor to that used by Max and Martin’s mother when she points out that such language has a psychological effect that can best be depicted as a *black hole*, from which there is no liberation or possibility of meaningful action. I have never heard parents say that they either can or will let go of the loved child. That they will *get over it* has no meaning for parents or for me as a therapist. On the contrary, I have learned that each unique lifeworld provides unique life-knowledge. I have found that maintaining an attachment to the living is more protective than *letting go*. It can make a difference when we find a way to speak about our children that can carry memories of them on in the lives of parents as part of the story of the family about itself.

*Therapist:* I am impressed about how you reflect around – and manage – your days. At the same time, I think that you can do this because you’re so strict about what you allow yourself to think about and do. I think this might get very demanding over time, and that it will be easy to strain yourself. You give so much to others and need to get something back. You also need acknowledgement for what you do. Who is there for you? Who sees what you do and fills up your storehouse with energy when you need it?

*Therapist:* Even though we’re separated, I can share almost everything with my boys’ father. He’s a very good dad to them and a co-parent with me. We share love for them and grief over losing them. And then I have my mother.

*Therapist:* In what way is she there for you?

*Mother:* She says that I’m the best mother in the world. She tells me all the time how proud she is of everything I do for Max and Martin.

She puts up with all my bad days and I never need to feel guilty when I complain to her. She's super important to me.

*Therapist:* So, your mother is someone you can always lean on when you need to. I'm glad to hear that. I also think that Max and Martin would say exactly the same thing about you. Are there other people who are significant, and who you know are there for you?

*Mother:* It always does me a lot of good being with these others who have children with the same diagnosis. The other parents. Our children are completely different just like other children are completely different. We parents are very different from one another too. We are a good, broad demographic group with completely different interests, and completely different backgrounds. But we have a common bond that is very strong. Being with other people who are going through the exact same thing as you are, is very healing. It's essential for coping with life, actually.

A dimension of therapeutic significance is the facilitation of conversations with other parents in similar situations. Such fellowship represents a special form of experiential knowledge in which language becomes a shared feature and the experience of living in anticipatory grief is subsequently recognizable without requiring many words or explanations. Heidegger (Lock & Strong, 2010) calls language *the house of being* in which we reside through social interactions and as response to our participation in life. Narratives of others can resonate and become understandable because they represent lived life that can communicate unspoken knowledge (Grasaasen, 2020). Even though parents are continuously overwhelmed by their emotions, the situation can change from one of *threat* to one of development of understanding in which *being-in-the-world* takes on a new shape (Svenaesus, 2011).

## The Power of Language and the Force of Dialogue

To speak is silver; to listen, gold. Each is both a challenge and an important part of the art of conversation. How we use language is thus essential to the creation of good conversations. Language is descriptive but also functional as linguistic action, because implicit to its use is used in

a particular context. We use it to perform actions such as to inform, explain or comfort. Thus, words are never neutral, and they have distinct consequences.

*Mother:* I'm grateful to be able to talk with you too. You know, after we were told about the boys' diagnosis, no one else has talked with us about death. You are the only one who mentions the word. When I'm at the hospital, my feelings are stirred up and I cry a lot. I feel that the people who work there feel that's difficult. I think maybe they avoid talking about things that make me show my feelings.

*Therapist:* I'm glad that our conversations are experienced as good, but I'm not sure I'm equally satisfied about why. Instead of getting help from those who should be there for you, you find you need to take care of them?

*Mother:* Yes, it feels that way. Sad stories, no one likes that. We all would rather hear that things go well in the end. It's hard of course in this situation.

*Therapist:* That is very sad that you have to go through that. No matter what it might concern, this isn't a burden you should have to carry.

*Mother:* No, but I have so many questions, there's so much I wonder about that even you can't help me to get answers to. It's not what I want, but now and then doubts about how the future will be push their way in. The boys have become heavier to manage and don't have as much space in our laps as before. It's as though their lives only just fit into a child's body. I wonder about how their lives will end, how that will happen. I think it's scary and frightening to think about. It's those sorts of things I could have used someone to ask about.

In meetings with parents, verbalization of relational experiences occurs, and reality is understood through speech acts. The way we speak will influence how the situation is experienced (Alvesson & Sköldb-berg, 2018). This aspect is particularly important in connection with disease and death. Parents in anticipatory grief seldom have the energy to be attentive to language and slide easily and unnoticed into whatever linguistic universe is offered to them. As conversation partners, we have both power and responsibility—"Words can bewitch us", warns Wittgenstein (1969). Escaping the word-games in which we participate is just as impossible as moving pieces in a chess game any way we wish. We

allow ourselves to be seduced into following the rules without thinking that we can simply just reject the whole game. The relational focus in dialogue and in social construction affords acceptance of a multiverse of meanings. When Sheila McNamee (2004) uses the term promiscuous to challenge us to cooperation this is so that we can be open to other theories as discursive alternatives. Cooperative constructions can improve our ability to be relationally engaged with those we are to help. We become sensitive to their stories as well as to our own in ways that allow us to be both receptive and relationally responsible (McNamee & Gergen, 1998). In encounters with difficult life situations, it is therefore a strength to question one's own ideas and remain open to the possibility of having different conversations. When we attempt to develop meanings that can be helpful to parents, it is their narratives that must be the conversational axis and their reality that is acknowledged (Anderson, 1997). It is interesting for me to note a sort of circular connection in this between the complexity of anticipatory grief and my own experience as therapist. Elements from different theoretical positions become complementary rather than contradictory, and multiple phenomena are then available for reflection. As a therapist, I can relate to the disciplinary perspectives I find useful instead of working on behalf of a single position. Max and Martin's diagnosis can be understood both as socially constructed and brought into existence by basic structures. In meetings with their parents, I can understand anticipatory grief as a biological basic structure that is part of what it means to be human, but which finds expression in relation to the social constructions of which the person is part. This is a matter both of nature and culture, explaining and understanding.

*The narratives in the text are fictional composites using elements drawn from different conversations with several parents. I have learnt so much from these, and I am very grateful for them Thank you to everyone!*

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