

**Let's share
our stories from the
edge**

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WORKING WITH THE VERY ILL

- **IT'S DIFFICULT.**
- **You need to be in good terms with mortality.**
- **Elements of the individual and family history make the work even more difficult.**
- **Supervision, staff groups, good relationships**
- **Balance between the very hard contents and the good things in life.**

WHAT TO TALK ABOUT WHEN TALKING ABOUT DEATH

- Clarifying what death means for the child (the accelerated development of the death concept = it is the irreversible cessation of the bodily functions)
- What the child thinks happens afterwards?
- Where is this information from?

STEPPING OUT OF THE FRAMES:

- True or not, believing that life does not end but goes on in another form is stress-reducing. Help is what helps. (The Lion King)
- Elisabeth Kübler-Ross : NDE
- Question: what is dying like?
- Answer: cold, pain, terror, loneliness, being tossed out into nothing, etc. == unconscious memories of birth

THE DEATH OF A MATE (1)

- **THEY KNOW IT.**
- **They want to know exactly what happened to them, what they felt and what they are feeling now.**
- **An exact report helps reducing anxiety intervowen with suggestions like: unlike you, he had this. His values were this, yours are different.**

THE DEATH OF A MATE 2

Visualizing the dead mate being now on the other side:

- What is his face like?
- What would you like to tell him?
- How does his/her face change upon hearing what you've just told?
- Tell him/her that we'll keep his/her memory and wish that he is well on the other side.

THE DEATH OF A MATE (3) FAQs

Q: Why did the other one die? Was this early death a punishment? Why did he get this disease? Why did I get this disease?

A: On this side we do not know. Life seems to be a school, and we have different tasks. His was to have this disease and still be a nice person.

THE DEATH OF A MATE (4): Mourning together

- **Children do not know how to mourn, they need somebody to show them the way**
- **Crying together in a close bodycontact**
- **Accompanying the dead one on the journey, sending nice thoughts to help them /praying for them as long as children ask for these rituals. This process used to last for 1-3 weeks.**

THE DONOR MUST DIE FIRST

- **Q: Am I waiting for a donor to die?**
- **A: Wrong question. You are waiting to make something good out of a stupid accident that happened independently of you.**
- **„Talking” to the donor**
- **In family constellations setting up the donor, the recipient and death clearly indicates the lives of the two are totally separate.**

THE KIDNEY OF A PARENT

Two difficult situations:

- The parent could be a living donor but they would not donate: this is painful for the child and a relief at the same time.
- The parent is a suitable donor and says yes: a huge anxiety in the child

Solution: „It is not your decision, you are the child, the big ones decide”

WORKING WITH PARENTS AND FAMILY

- **Parents need to know:**

Children are in tune with, and accept their fate. Their disease being a burden and a source of pain for the parents worries them a lot.

Parent's questions:

- **Is my child's disease a punishment for something I did?**

WORKING WITH PARENTS (2)

Guilty feelings for the child's disease

- **Is it a punishment for something I did/did not**
- **Did I do something wrong during my pregnancy?**
- **Why me?**

Helping them through the five phases.

Family therapy: fixing the split between the healthy and the sick system in the family

DORBI, GÉNE



THANK YOU FOR BEING HERE!

