

## Presentation

My name is Lise-Lotte, I 'm 48 years old and I've been married for almost 24 years to my husband Jesper. Together we have two grown-up and well-balanced girls.

I am a trained social worker and I work a couple of hours each day at an institution for people with mental disabilities.

In 2002 I was diagnosed with Paranoid Schizophrenia after a long and very stressfull hospitalization.

When I'm not at work I enjoy walking with my dog, painting, listening to music and I try to keep stressless at all times. I am good with animals and small kids and am generally a very social and outgoing person.

## Cue cards

Maybe you wonder why I have cards in my hand – the reason is simple.

When I am in stressed situations, I have a lot of noise in my head.

Voices telling me that I'm boring, that I'm stupid and embarrassing. Sometimes my head melts down and my brain goes black.

## Initiation / prolog

I was born with a very sensitive mind – and with a mother who (according to professionals) **may have had an undiagnosed** personality disorder – I grew up with my head filled with distrust. Distrust to everything and everyone around me – to the entire world.

I never experienced the feeling of being loved and cared for – I only felt tolerated.

Fear was my true companion from a very young age.

The feeling of being persecuted came to me when I started public school. At that time I was severely bullied and even beaten up – and I was always afraid ... afraid of assaults, rape and death everywhere I went.

I developed a feeling of being watched through my teenage years and that was when the first voices and suicidal thoughts showed up in my head.

Slowly I got more and more paranoid and for several years I was convinced that my mother could read my thoughts. I was convinced that she went through my things when I wasn't home – so I couldn't hide anything from her.

When I met my future husband I was 18 years old and didn't understand at all what he saw in me. I turned him away over and over - I had no self- confidence and intimacy was hard for me – almost impossible.

Despite all of that, today I've ended up with:

An education, getting married and having children.

## Hospitalization

Let me take you back to year 2000 (31 years old) when everything seriously overthrewed me and I was hospitalized.

Before then, several months had passed with loss of appetite and increasing paranoia, delusions and anxiety.

My weight was down to 46 kilos and when I was hospitalized my calcium level was life-threatening low.

Personally, I had **no** problems with my weight loss. I was mega proud of my (skinny look) thin appearance and I didn't realize the risk (heart attack) connected with low calcium at that time.

I had no experience with the psychiatric system – but had seen the old movie “One Flew Over the Cuckoo's Nest” – and when I was hospitalized I was convinced that the story in this movie would also happen to me.

It was a very long and very tough hospitalization - more than 1 year. I saw the staff as my enemies, and at the same time they did not understand my suffering but struggled to get a treatment alliance with me.

Is was one long struggle defined by detainment, many suicide attempts, self-destructive behavior, no medication, isolation, hearing voices, many conflicts and a lack of understanding from professionals of what and who they were dealing with.

But the moment I was moved to the Emergency and they asked me what **I** wanted – something began to happen.

My biggest wish was simply to go home and surprisingly they followed my wish and choose to cancel my 1 year long detainment.

The staff made it clear to me that they still wanted to help me and wanted me to stay at the hospital – but it had to be optional.

I tell You – the ink on the release papers wasn't even dry before I sat on the train heading home – home to my beloved girls – home to my family.

I was home for some months – still very ill. Hearing voices which I thought was the staff at the hospital. I was convinced there was a huge conspiracy against me – and that everybody was part of this conspiracy - even my husband Jesper. And I was convinced that the conspiracy was planning to remove my two girls – just 4 and 6 years old.

I was terrified – what if the voices were really telling the truth. That I was a really evil person – hurting everyone around me I – even my beloved girls.

Because of this, I even had self- destructive behavior at home and many suicide attempts and thoughts.

The voices were very painful for me and one day when I was home alone, I decided to find the hospital staff that I was clearly hearing saying bad things about me. I ended up in the livingroom. The tv was on. It was a tv show I knew well – an old show about refurbishing houses.

I stand in front of the TV and suddenly the host starts saying really bad things about me. THAT is simply too weird – Like I said I know this show – and it is NOT about me and the host for sure doesn't know me!

I remember that while I was studying I learned that if the radio or TV is “talking” to you or about you ... it's not good. The experience scared me, but still I would not go back to hospital – so I decided not to tell anyone about the episode. Besides, we were just about to go on a family trip to Disneyland, me, my husband and the children – to celebrate that “mom” is back home. So - no way I'm going to tell anyone – I wouldn't ruin the trip.

We go to Disneyland – I feel awful, I'm hallucinating a lot. But I stick it out and go home with the feeling that I have done something good for my children - I have been giving them an experience with their mom. Therefore I decide to withdraw before I do more damage to them than the voices are telling me I have already done.

The night we come home from Disneyland I once again take an overdose of antihistamines and in my daze I hallucinate quite strongly.

“Picture this – I am standing in the middle of the room. It is my youngest daughter – Frederikke's – room. The door is locked but at the ceiling I clearly see cameras all around. The cameras are filming me. I see the red spot blinking. I clearly hear the hospital staff laughing, making fun of me and my situation.

Because I hold baby Frederikke in my hands – she is very ill – she is cold and she is pale and is getting more cold and more pale. In the end she turns totally white and ice cold - and she dies. I'm screaming my heart out. I am terrified that my daughter is dead and that the staff is just laughing at me and won't help me.

My screaming wakes up Jesper, who is deep asleep in the bedroom next door. In fact I had crawled into Frederikke's room. He asks me – “why are you screaming?” I am crying and with tears in my eyes I am telling him about Frederikke's death and the staff's behaviour.

Jesper looks at me and then he says - “don't you remember – the girls are sleeping at grandma's tonight?” Then he realizes how psychotic I am and he takes me to the hospital”

## **Hospitalized again**

This time my hospitalization is totally different – way more constructive. With help from Jesper (my husband) I tell the staff about my hallucinations and about the TV talking about me – and suddenly someone important from the staff understands my disorder.

This makes it easier to convince me to start medical treatment and for the first time there is an alliance between me and the staff, where we can work together.

The agreement is that I can go home and visit the children every day – if I agree to step up on antipsychotic medicine and participate in cognitive therapy.

The arrangement works well for me for about a year. Actually I am hospitalized most of the time – but I manage to keep a strong connection to my family and try to be at home as much as possible.

When I finally leave the hospital in 2002 – after more than 2 years of hospitalization, a diagnosis and a battery of medication richer – I am not the person standing in front of You today. Big amounts of sedative medicine made me idle and I found myself in a constant daze.

## **No capability of initiative**

I had no room for anybody – only for the girls and Jesper

The days where I was not in hospital for treatment/therapy, I spent drifting away on the couch. I had minimal self-care and had to make agreements with myself regarding bath, laundry, lunch boxes etc.

### **The rest of the time:**

Went by on the couch – but without sleeping. Instead I went into the world of my head filled with voices and conspiracy thinking. The only thing that could bring me back to reality was relaxing on the couch with the children – watching Disney movies under the ball blanket and being as close to them as possible.

No matter how ugly and psychotic my world was I NEVER lost faith in or the love to my girls.

Parenthood was so deeply rooted in me that I managed to be there for the them – all the way.

Besides the deep love and capability to take care of my children I never lost my self-care abilities.

- I was not a victim
- Jesper didn't see me as a victim

For example. I insisted that I SHOULD participate in the daily routines – despite my lack of energy and initiative. Saturday was the weekly cleaning day. Frankly this meant:

- Me: dusting
- Jesper: Watering the flowers, vacuuming, cleaning the kitchen and bathroom – and dusting where I had just been.

Our family and friends also coped very well handling the ill/psychotic Lise-Lotte. Among others my closest friend chose me as godmother for her two children despite the fact that I was hospitalized and very ill during the christening.

In fact I was never “hidden away”.

I was invited to get togethers – and participated even though I couldn't stand it.

- I couldn't handle other people than my closest family
- I felt bad when there were more people
- I participated only because of Jesper and the girls.
- I oftened just sat totally quiet during dinners
- Got paranoid and could hear the rest of the party saying bad things about me.

All I could do was just to sit quietly or hide in the kitchen or the bathroom.

Wow – the amount of sentences, topics and talks during those nights I have turned and twisted and analyzed on the way home.

And a Very patient Jesper who had to repeat over and over that

NO ONE had talked about me

NO ONE were angry at me

NO ONE hated me

Jesper has been – and still is – my anchor and my firm rock – whenever my world seems to tumble.

Today I can be scared when thinking about how my life would have been, IF I had had the chance to live like I mostly wanted – isolated. Then I had probably lost a lot of the deep and good relations I have today.

The huge and fantastic network I have today is the most important to me along with my husband and kids. In my network I can always find comfort and help if things are going bad or if my husband cannot be by my side.

## Months become years

Slowly the amount of antipsychotic medicine was raised and I could get rid of the calming and deadening medication.

My ONLY contact with psychiatry was regular conversations with the district nurse who controlled all my medication. I still was anxious and paranoid and didn't want to talk to doctors at all.

- Not my own doctor
- Not the doctors at the hospital.

During those years it was mainly Jesper who took care of me on a daily basis.

He took care of the daily duties and chores and of the girls.

Slowly I got better – helped by the conversations and the medicine.

## The day came

I had to end my sessions with the district psychiatry and it was time to take care of the issue or problem that I couldn't/wouldn't use my own GP (General practitioner).

Lis (my district nurse) simply

- chooses a new GP for me (who she knew from psychiatry)
- She literally dropped me off at the GP and gave him a thorough account.
- She also ordered him to take very good care of me.

This new doctor became the start of a quite new recovery process.

- Slowly he gains my trust / and slowly I begin to be able to form alliances. This He did most importantly by:
  - o ALWAYS having the time and space
  - o Being authentic and honest
  - o Being very caring.

During the years, our conversations/the consultations become more and more present and confidential. Ejvind (my GP) also let me keep the lead and my self-determination.

-Wishes for weaning out the medicine was tried.

-I was taken care of – both physical and mentally – when required.

-I never had the feeling of going in vain when I consulted him

Slowly the medical center - the same as I have today – became my lifeline those hours Jesper was at work and took care of his job.

Actually, I managed to stay out of the psychiatric system for 14 years this way.

My 2 long periods of hospitalization and 38 registered suicide attempts – are deeply rooted in me and are very traumatizing for me. I spent a lot of energy on telling both my GP and new district nurse that they should NEVER hospitalize me again. At that time I believed that another hospitalization would make me ill - and that the system (because of that) would never let me out again.

I had a very tough year last year, life became too hard. I lost my beloved foster dad and my fantastic GP to cancer within a few months. It overturned me completely and I went into a psychosis and a total meltdown – a new hospitalization was required.

Fortunately my district nurse had managed – in peace time – to put into words what I needed to make things work, IF I had to be hospitalized again.

- No locked doors
- short term hospitalization
- Max freedom

Those were my – a bit utopian wishes.

But I realized that the psychiatric system after all had seen some positive changes during the years 2002-2016. The doors were open for me – even at night.

I was met as a human being – and not just as a medical story and diagnosis – that was a very good experience.

During my last hospitalization I had a sensory profile made up. It showed that I'm popping out on all parameters. A number of new relaxation tools and techniques have been introduced to me which have had a positive effect on my daily life. Time to rest, contemplation and calming music – and it means that I at the moment have reduced my need for medication by 50 percent.

Despite this I live a normal family life with all that it takes of daily duties and social gatherings. I take care of my job every morning from 7 – 9.30 and even though it is just a “small” job (10 hours a week) – it is a development in my recovery process which I welcome.

Back in 2002 it was very hard for me to accept that I was actually not able to work – and that I had to get used to a life of early retirement.

I was very self-stigmatizing and found it very hard. When I was among other people, I found questions like “So What are You doing for a living” or “Are You having a day off” very hard. It was SO hard for me to admit that I had EVERY DAY off and was on early retirement.

I'm still on early retirement – but today that definition is very low on the scale from which I define myself. TODAY I'm first of all a social worker at “Langagerparken” A job that gives me SO much.

I've got a place I belong and my fantastic colleagues are very caring and take very good care of me. And my job is the exact same as my colleagues. It is a real social worker job. And if I'm sometimes absent and my colleagues run faster or a substitute has to be called in, I know that the job I do is important and that a lot of people appreciate that I come in every morning and get the residents up and off to work.

On top of this, there is of course a financial benefit in it for me. And even though we are not talking about a fortune - it is to me and my family. Just enough to make life a bit funnier.

With a diagnosis like mine we all know that not every day is just fun. BUT we try to keep focus and make the best of the good days, and during my good times when I'm feeling well, we use my extra income on – for instance holidays, getaways and anything else that gives our life that extra strength to help us through the bad days. On bad days, it's very important to me to have these good memories – telling me all the good in life. Because - once in a while – I get overwhelmed by old patterns, self-destructive behavior and suicidal thoughts, I still have my doubts about the meaning of life – and asks myself - is it worth living?

Today I dare call my life a fantastic life – it has become easier to ask for help before my world is tumbling again. I do love life – the good life – and I do want it. I love my fantastic family, my many many friends – and THAT my stupid brain is not going to control me. It is not going to win!

I am proud and very happy about where I've landed in life. From being the child that no one could love till today (on most days) feeling a success - with a rich life full of love, family, friends and a job.

Finally – a few thoughts on whether anyone or anything could have made a difference for me while I was most ill

### **I can say:**

While I was hospitalized fortunately a lot of people were around taking good care of my girls. For instance, my oldest had a classmate whose mother was very kind to invite on playdates which could include Christmas-baking – then my husband didn't have to stress over that sort of things.

But I actually think that during that time – I could have used all that positive feedback which I receive in bundles from my local community today - now that it is public known that I'm ill and have my diagnosis.

Today I think that if anyone should have done a difference to me while being ill – it should have been neighbors inviting me for a cup of coffee – or having the courage to ask all the difficult questions – like they do today.

If somebody had had the courage to meet me as a human being – more than being afraid of saying or asking the “wrong” things.

Let me make it clear – NOBODY can say anything to a mentally ill person that makes them more ill.

Mentally ill people are also just humans – AND NO ONE IS ONLY THEIR DIAGNOSIS!!!

As You meet people with diabetes as humans – I wish that I am met as Lise-Lotte – I wish to be met as ME. With all that I entail of good and bad sides.

**NO ONE IS ONLY THEIR DIAGNOSIS !!!!!**