



Stories of Care

Navigating mental illness together





INTRODUCTION	6
1 ANNA - A MOTHER CARING FOR HER SON	7
2 PATRIZIA - A DAUGHTER CARING FOR HER MOTHER	9
3 WALTER - A FATHER CARING FOR HIS SON	11
4 EVA - A MOTHER CARING FOR HER SON	13
5 RITHA - A MOTHER CARING FOR HER SON	15
6 DANIELA - A MOTHER CARING FOR HER SON	17
7 AMELIE - A MOTHER CARING FOR HER SON	20
8 ILSE - A MOTHER CARING FOR HER SON	22
9 MICHAEL - A FATHER CARING FOR HIS SON	24
10 LUISE - A MOTHER CARING FOR HER DAUGHTER	26
11 KARIN - A MOTHER CARING FOR HER DAUGHTER	28
12 FLORA - A SISTER CARING FOR HER BROTHER	30
13 ANJA - A SISTER CARING FOR HER BROTHER	32
14 CAROLA - A SISTER CARING FOR HER BROTHER	34
15 TANJA - A MOTHER CARING FOR HER SON	36
16 LOTTA - A MOTHER CARING FOR HER SON	38
17 ELISABETH - A MOTHER CARING FOR HER SON	41
18 JULIA - A MOTHER CARING FOR HER SON	43





19 BERNADETTE - A MOTHER CARING FOR HER SON	45
20 SIGRID - A MOTHER CARING FOR HER DAUGHTER	47
21 RALUCA - A MOTHER CARING FOR HER DAUGHTER	50
22 HELGA - A MOTHER CARING FOR HER SON	52
23 ULRIKE - A MOTHER CARING FOR HER DAUGHTER	54
24 THERESA - LIVING TOGETHER WITH BOTH A SICK SON AND A SICK HUSBAND	56
25 LUCIA - A MOTHER CARING FOR HER SON	58
26 KLAUS - A FATHER CARING FOR HIS SON	60
27 MARLENE - A MOTHER CARING FOR HER DAUGHTER	62
28 CELINE - A DAUGHTER CARING FOR HER MOTHER	64
29 NATASCHA - A MOTHER CARING FOR HER SON	67
30 OLIVIA - A SISTER CARING FOR HER BROTHER	69
31 JANA - A SISTER CARING FOR HER SISTER	72
32 HELENE - A MOTHER CARING FOR HER SON	75
33 IRENE - A MOTHER CARING FOR HER DAUGHTER	78
34 CHARLOTTE - A MOTHER CARING FOR HER DAUGHTER	81
35 MONIKA - A MOTHER CARING FOR HER SON	83
36 VERONIKA - A MOTHER CARING FOR HER SON	86
37 DOROTEA - A SISTER CARING FOR HER BROTHER	88





38 SUSANNE - A MOTHER CARING FOR HER SON	90
39 MELINA - A DAUGHTER CARING FOR HER MOTHER	92
40 TAMARA - A WIFE CARING FOR HER HUSBAND	94
41 CORNELIA - A MOTHER CARING FOR HER SON	97
42 ALBERT - A BROTHER CARING FOR HIS BROTHER	100
43 FRANZ - A FATHER CARING FOR HIS SON	102
44 GUDRUN - A MOTHER CARING FOR HER SON	105
45 PETRA - A MOTHER CARING FOR HER SON	108
46 KONRAD - A FATHER CARING FOR HIS SON	111
47 ALICE - A SISTER CARING FOR HER BROTHER	114
48 HANS - A FATHER CARING FOR HIS SON	116
49 JOCHEN - A FATHER CARING FOR HIS SON	119
50 LUDWIG - A FATHER CARING FOR HIS SON	121
51 MARIANA - A MOTHER CARING FOR HER DAUGHTER	123
52 GEORGE - A BROTHER CARING FOR HIS SISTER	125
53 ROZALIA - A MOTHER CARING FOR HER DAUGHTER	127
54 ADRIANA - A MOTHER CARING FOR HER DAUGHTER	129
55 LIVIU - A FATHER CARING FOR HIS SON	131
56 ANI - A MOTHER CARING FOR HER DAUGHTER	133





Stories of Care

Navigating mental illness together

57 SORIN - A FATHER CARING FOR HIS SON

135

58 BIANCA - A MOTHER CARING FOR HER SON

137

59 IULIA - A MOTHER CARING FOR HER DAUGHTER

139

60 VICTORIA - A MOTHER CARING FOR HER DAUGHTER

141





Introduction

Caring for a loved one with schizophrenia is a journey marked by uncertainty, resilience, and profound emotional complexity. This collection of 60 personal stories, told by mothers, fathers, sisters, brothers, daughters, and spouses, offers an intimate glimpse into the daily realities of those living alongside this serious mental illness. Each narrative reveals the unique challenges faced by caregivers, grappling with stigma, navigating healthcare systems, and struggling with the constant tension between providing support and maintaining boundaries.

These stories span decades and generations, yet they share common themes: the initial confusion at the onset of symptoms, the turmoil of delayed diagnoses, the heartache of watching a loved one change, and the quiet strength it takes to persevere. Whether it's the guilt of a mother questioning past decisions, a sister risking her safety to protect a brother, or a father reconciling pride with fear, these voices reflect both the diversity and the shared humanity of caregiving.

This compilation was developed within the framework of the Erasmus+ project “Transforming the case stories of families affected by mental illness into learning and awareness raising tools” (Project number: 2023-2-RO01-KA210-ADU-000182427), co-funded by the European Union. Running from March 1 to December 31, 2024, the project aims to turn real-life experiences into meaningful educational resources, promote awareness, and foster empathy and understanding across communities and institutions.

By giving voice to those who support, endure, and advocate - often in silence - this document honors their stories and underscores the urgent need for greater support structures and systemic change.





1 Anna - a mother caring for her son

Anna is 54 years old and the mother of Richard who is 34 and was diagnosed with schizophrenia at the age of 22. Anna's story revolves around the topic of guilt with, on the one hand, her son blaming his parents and siblings of being responsible for his disease, on the other hand, having doubts herself whether she might have overlooked early signs of the approaching calamity. (67 words)

“How could I have done things differently, and why didn't I react earlier, more proactively?”

In our case, the illness did not break out all at once and was not diagnosed as such. It was a slow development of increasing depression during puberty, difficulties at school and then, at the age of 22, the first recognisable psychosis, which led to the first visit to a psychiatrist.

Then there were more and more symptoms of schizophrenia, but no diagnosis. As a family, we were more concerned with organising our daily lives between doctor's appointments, attempts at work and therapists, and how we all lived together. There was little room for feelings of guilt. Rather, the question was: why does this have to happen to us? Our son in particular asked this question daily and repeatedly, always blaming other family members and events, especially the actions and attitudes of his parents, their behaviour and relationship with his younger brothers. It still comes up from time to time, six to eight years later.

At first, I rejected everything, probably out of self-protection. Over time, and with better communication skills, I looked for understandable arguments against it, which also helped me in my argument with myself. Sometimes we agree on a point of view, and when we stubbornly don't, I conclude that I have reached my end, so to speak, and suggest that he continue the conversation with the psychotherapist. I do this particularly when he directs his accusations at other, absent members of the family. In this situation, I think it can help to remember that even without illness, many people tend to look for someone to blame when reality differs from their expectations.

Luckily, I personally have not experienced any blame from my social environment, but this is partly because I have a constantly changing work environment due to my job. Friends, neighbours and acquaintances who have known our children from an early age, even before the onset of the disease, have always been very understanding.





With other people, the contact is not so close as to encourage such comments. Of course, the network of relationships narrows over time. The reason for this was many years ago when my husband told me to be careful what I said to whom. When he was up for promotion, a senior colleague allegedly told their mutual boss and others that he should put his own family in order first.

We are more careful about the people we are close to and who we want to be involved in our family situation. When dealing with others, there is always the desire to protect the person with the illness and, of course, to protect ourselves. This can affect our spontaneity in forming new relationships, but the quality of the relationships should actually improve.

Since the two younger siblings of our son with the disease, who are two years apart, are 'perfectly normal', and since I repeatedly sought professional help from the moment I realised that something seemed to be wrong, I have come to the conclusion in these mental confrontations that I acted to the best of my knowledge and belief at the time.

That calms my thoughts, but not my feelings, which come back in the sleepless hours of the night and cannot be explained away. How could you have done things differently, and why didn't you react earlier, more proactively? Why didn't you pay more attention to the symptoms at the time? What would have been recognisable at what point?

Main topics covered in this story

Behaviour and disease manifestations of the son Richard:

Other psychopathological symptoms; Blaming; Disease course

Experiences and emotions of the mother Anna:

Distress; Care dilemma – more or less care and control

Other main topics:

Employment, Education, Finances; Services and Professionals; Causal assumptions / theories; Stigma, Discrimination, Social network, Public realm



2 Patrizia - a daughter caring for her mother

Patrizia who is now 54 years old, reflects on the ups and downs of her difficult relationship with her sick mother over all of their lives - starting from early childhood, when Patrizia had to take on parts of the parent role until the death of her mother at the age of 74. (53 words)

"When I was 14 or 15, my father asked me to help take care of my mother and run the household."

My mother has suffered from a mental illness for as long as I can remember. It took me a long time to realise what it was: looking back, I think she may have suffered from postnatal depression after I was born. Our GP saw her often, but it was not possible to make a diagnosis at the time.

When I was 2, the first psychosis occurred: my mother stopped sleeping, became loud, heard voices on the radio and behaved completely inappropriately. My father reached his limits and was unable to get any real help. Then she was admitted to a psychiatric hospital for the first time: I was only allowed to see her from the outside through the fence, nothing was explained or said to me.

The following years of my childhood were a constant up and down: complete withdrawal, where she often lay in bed for months watching the world go to pieces, alternated with psychoses, arguments, insomnia and, unfortunately, alcohol. My brother and I were placed with different relatives and no one ever talked to us about why our mother was behaving like this. They said she was ill again.

I couldn't talk to anyone about my mother's illness, on the contrary, it was like a family secret. School, on the other hand, was a safe haven for me, where I didn't have any obvious problems. So, I led a double life: at home my mother was seriously ill, but at school there was nothing out of the ordinary. I often reached my limits, but I didn't get any support. When I was 14 or 15, my father asked me to help take care of my mother and run the household.

Even in Austria in the 1970s, attitudes towards mental illness were sometimes catastrophic: the disease models of the early 1940s were still too prevalent in people's minds, and my mother not only suffered from a very serious illness, she was also shunned and ridiculed.

My father and most of the other relatives had no understanding of her illness. Thus, it was not possible for her to accept it and live with it. All her life, her own illness was her enemy; I often heard her say: I would rather be in a wheelchair than have this disease.



In between her psychotic episodes she was a wonderful person, full of love, intelligent and warm-hearted. There were many painful experiences associated with her illness and its side effects. But I would never want to have a different mother!

Over time, better medication came on the market and for a few years she was no longer ill every year. Unfortunately, the side effects of the medication began to take their toll and the frequent psychotic episodes that lasted for months took their toll. She changed as a person, had hardly any interests anymore, and developed some physical illnesses.

My mother did not live very long; she spent her last years in a nursing home. She was given more and more medication, in ever-increasing doses.

I was a very good student and found it easy to learn. I went on to university, but at first, I found it difficult to leave my parents' house because I felt I was abandoning my mother. My parents were very open about this.

Because I was very afraid of exams at the beginning of my studies, I went to a general practitioner to get help. I told her my family history, and she referred me to a psychiatrist with the diagnosis 'mother schizoaffective'. I was lucky, that the doctor focused on my examination fears and did not see me in terms of a possible family illness of a psychosis.

I wish that today's children and teenagers with a similar fate would receive more support and understanding! Sometimes a wordless hug, a warm chocolate drink and a piece of cake would have been enough to help me.

Main topics covered in this story

Behaviour and disease manifestations of the mother Amalie:

Psychotic symptoms; Inactivity/Blunting; Other psychopathological symptoms; Strange behaviour (not aggressive); Disease course

Experiences and emotions of the daughter Patrizia:

Distress; Care dilemma – more or less care and control; Other challenges; Appraisal of others

Other main topics:

Relationships within the family of the patient; Physical health of family member /patient; Services and Professionals; Therapy-related issues; Information deficits; Stigma, Discrimination, Social network, Public realm





3 Walter - a father caring for his son

Walter is the 47-year-old father of Andreas who is now 25 and in retrospect exhibited symptoms of schizophrenia during puberty, which were not recognised as such. The story is about repeated early violent incidents within the family and a delayed diagnosis of schizophrenia at a forensic psychiatric unit, when Andreas was 18, which finally led to successful treatment and rehabilitation. (60 words)

"When the psychiatrist explained the illness to me, I cried for hours"

No one who has not experienced something similar to what our family has experienced, will understand everything I am trying to say.

I am married and have three children. My son Andreas was very well-behaved and quiet as a child, perhaps a little too quiet and unemotional in retrospect. But with puberty everything changed abruptly. His school performance got worse and worse, if he even got up to go to school at all. He became loud, aggressive and often didn't come home for days. At first my wife and I thought he was on drugs or involved in crime.

The situation escalated and he became violent. He beat up my wife and his siblings. After an argument with me, he hit me so hard that I ended up with fractures in my face. So, I threw him out of our apartment and told him to go and live with my father, his grandfather. Then the unthinkable happened: he beat up my father so badly that he had to be taken to hospital. The neighbours called the police and he was taken to a secure psychiatric ward. He was 18 at the time.

On the psychiatric ward he was calm, dressed in black as always, with a hoodie. The doctors didn't know what to do with him and considered discharging him. However, my father's injuries were too severe and he was reported.

In the end, he was admitted to forensic psychiatry, and that was his best luck. There, a psychiatrist spent a lot of time with him and eventually diagnosed him with severe juvenile schizophrenia. It turned out that he not only heard imperative voices, but also had visual hallucinations.

When the psychiatrist explained the illness to me, I cried for hours. I was sad that my son had this condition, but also ashamed and hurt that we hadn't noticed it for so long.

He was given the right medication, and received psychotherapy and psychoeducation. He has greeted us with a smile for years now! My wife and I were so relieved. He spent a year and a





half in the forensic ward, then in various rehabilitation centres, and still lives in a shared flat. As part of a programme, he was able to complete a professional training as a gardener, which he really enjoys because it allows him to be in nature. He still finds it difficult to interact with people, but we, his family, understand and support him wherever we can.

I am very proud of Andreas and happy that we have made it through the hardest time, which was before he received the diagnosis in the forensic unit. I don't know what the future holds. I hope that there will be many happy moments, that the family will be strong and that other mentally ill people will also find such great psychiatrists.



Main topics covered in this story

Behaviour and disease manifestations of the son Andreas:

Psychotic symptoms; Strange behaviour (not aggressive); Aggressive behaviour; Disease course

Experiences and emotions of the father Walter:

Distress; Appraisal of others; Positive attitudes of family member

Other main topics:

Relationships within the family of patient; Employment, Education, Finances of family member and patient; Services and Professionals; Therapy-related issues; Causal assumptions/theories; Legal issues and police involvement





4 Eva - a mother caring for her son

Eva is the 62-year-old mother of Michael, who was diagnosed with schizophrenia 10 years ago at the age of 21. Eva describes how being included in Michael's paranoid thoughts during acute episodes made her completely powerless. While Michael is currently doing better, Eva vividly describes how she is tormented all the time by fear of a relapse. (57 words)

"I have the impression that he sees me, but no longer trusts me, as if I might want to harm him too"

It hangs over me like the sword of Damocles, ready to fall at any time. Currently, my son Michael is fine, he organises his daily routine, can deal with his illness, does sport and maintains his social contacts. But it can happen again, like 10 years ago for the first time, 8 years ago again and a year ago in a milder form.

When it happens, he becomes someone else within a few days, is nervous with a piercing gaze, pacing around, talking about things that only he perceives, anxious, suspicious. I have the impression that he sees me but no longer trusts me, as if I might want to harm him too. This scares me a lot, which in turn puts him under pressure because he doesn't want me to worry.

Last time, my advice to see his psychiatrist as soon as possible was dismissed with the comment that this time he will surely manage on his own. He probably realized that he was not quite well, but thought he would manage. His confusion was increasing, as was my fear. He no longer spoke a lot, hardly called at all, and when I called him, he often didn't pick up the phone until one day he could no longer be reached at all.

I drove to his apartment, but he didn't open. From the street, I could see that the light was on in his living room, and I sat in the car and watched to see if I can perceive any sign of life. My thoughts were going round in circles: what could have happened, where is he, how is he, and above all, what can I do, how can I get to him to help him, what could I do to get him to let me help him? After a while, I saw movement in his room, thank God, he's there! I called him, no answer, I rang the doorbell again, he doesn't open. Why isn't he responding? I drove home, at least I saw that he was still alive, that calmed me a little.

It would come back the following day, maybe he might open the door then. The next day he opened the door, I was so glad! However, he hardly responded to my questions, probably because there were too many.





His apartment was in a terrible state, it looked as if he had been searching for something, all the drawers and cupboards were open, his Xbox had been taken apart, and he had even opened the cover of the air exhaust in the bathroom. Unfortunately, he couldn't eat anymore, everything would have been poisoned, even the cigarettes would contain poison.

So, he was even worse off than I had assumed. I casually asked if a doctor's visit might help him, but he said no way, the doctor is also in league with those who poison his food and maybe I'm one of them because I want him to go there. So, it was better not to say anything, otherwise I would completely lose contact with him. I felt completely powerless, there was nothing more I could do for him.....

Many things had to happen before my son finally allowed himself to be helped. Stays in various institutions, years of therapy and lots of medication followed, and a lot of work on himself was necessary.

At the moment he is doing well again, but for how long? The illness persists, the sword of Damocles continues to hang over us. I try not to think about it, but is that possible?

Main topics covered in this story

Behaviour and disease manifestations of the son Michael:

Psychotic symptoms; Disorganised/Incoherent behaviour; Other psychopathological symptoms; Strange behaviour (not aggressive); Disease course

Experiences and emotions of the mother Eva:

Distress; Care dilemma – more or less care and control; Other challenges; Appraisal of others

Other main topics:

Services and Professionals; Therapy-related issues





5 Ritha - a mother caring for her son

Ritha is the 59-year-old mother of Rudolf, who is now 34 years old and was diagnosed with paranoid schizophrenia, when he was 19. Ritha reports how her son's violent behaviour in public sent the family into turmoil and resulted in his institutionalisation in a forensic psychiatric unit for several years, with Rudolf being now discharged but living under severe restrictions. (60 words)

“When he ran off into the woods one day without saying a word, we searched for him for hours”

I am the mother of an adult son who suffers from paranoid schizophrenia. He has had several psychotic episodes which have been incredibly stressful and painful for all of us - especially for me as a mother.

After Rudolf had already experienced a psychosis and had been prescribed a low dose of an antipsychotic, his doctor had warned him that the use of cannabis could trigger further psychoses. As my son refused to see any connection between smoking cannabis and his illness, he asked me to accompany him to a psychiatrist who was specialised in treating drug addicts.

The psychiatrist said that the neuroleptic was not necessary and prescribed an antidepressant instead. At another appointment, the doctor even praised my son for using cannabis in a vaporiser instead of a cigarette. My concerns about changes in his behaviour and strange grimaces, which I had observed even before the first psychosis, were dismissed by the doctor with a smile.

Just two weeks later, my son was so delusional that he saw enemies everywhere and refused to be helped. He was restless, smoked excessive amounts of cannabis and hardly slept.

When he ran off into the woods one day without saying a word, we searched for him for hours and finally found him in a neighbouring village. With the help of the police, we managed to get him into an ambulance that took him to a hospital. This was the second time I had felt that a psychiatrist's assessment was completely out of touch with reality.

Of course, nothing got better. On the contrary, two weeks later, in a delusional state, my son injured several people, believing that they were zombies and that he was the last survivor. Although the police were aware of the first incidents, they only intervened when a man fell to the ground during the attack and suffered a serious head injury.





Then the justice system reacted with full force: he was arrested, remanded in custody and spent two months in a psychiatric hospital. As soon as he began to recover, he was transferred to a prison for ten months without adequate treatment. After the court hearing, in which he was declared as legally incompetent but also dangerous because of what had happened, he was sent to a forensic institution for an indefinite period.

The following years were terrible for all of us. The powerlessness, worry and uncertainty about how long Rudolf would have to stay there weighed heavily on us. On the other hand, at least we knew he was safe there. I never thought that one day I would be happy that my son was locked up, but there I was. The psychotic episodes had traumatised me so much that this feeling of security was more bearable than what we had experienced before.

Fortunately, Rudolf's development has been very positive. After two and a half years he was discharged from the forensic psychiatric institution. However, he was subject to strict rules: he had to live in an aftercare residential facility, attend regular medical appointments, report to the probation service and follow a daily structure - for the last five years. This period is now coming to an end.

My son is doing quite well now, but the illness and its consequences have left their mark. His resilience is very limited. He is disturbed by large numbers of people and loud or continuous noises. He also suffers from the side effects of the neuroleptics, which he now takes regularly in the form of depot injections.

Nevertheless, he seems to have realised that he can only lead a semi-normal life if he takes his medication and stays away from alcohol and drugs. I really hope he continues to see it that way - because I am so afraid of having to go through this nightmare all over again.

Main topics covered in this story

Behaviour and disease manifestations of the son Rudolf:

Psychotic symptoms; Other psychopathological symptoms; Strange behaviour (not aggressive); Aggressive behaviour; Insight into illness/Compliance with therapy; Being stressed by external factors; Disease course

Experiences and emotions of the mother Ritha:

Distress; Other challenges; Appraisal of others; Positive attitudes of family member

Other main topics:

Physical health of family member/patient; Services and Professionals; Therapy-related issues; Legal issues and police involvement



6 Daniela - a mother caring for her son

Daniela is the 68-year-old mother of Dorian, who received the diagnosis of schizophrenia 22 years ago when he was 20 years old. Daniela describes how her son's childhood was characterized by increasing behavioural problems from kindergarten onwards and that, when finally, as a young adult Dorian received the diagnosis of schizophrenia it came as a shock, but that with the right therapy Dorian has learned to live with the disease. (70 words)

"I tried to set rules, to protect him, but I was too weak"

I still remember the first few years with my two sons, Markus and Dorian. It was clear to me early on that the two were very different. While Markus – the older of the two – was able to adapt easily to new situations and behaved calmly and thoughtfully, Dorian was always a bit different. He was more impulsive, thoughtful, often introverted, and sometimes he seemed to be in his own world. But every child is different, and I never saw that as a problem – until the first difficulties arose.

Already in kindergarten, Dorian was not as carefree as the other children. He had trouble fitting in, had a hard time dealing with change, and often withdrew. It continued in a similar way in elementary school, and when he finally came to high school, it did not get any easier. There he was repeatedly compared to his older brother. Markus was calmer, more adapted, and knew how to fit into society. - I remember one of his favourite sayings: 'You have to know when to stop.' I think that's a good description of the difference between the two of them. Markus knew when enough was enough, when he had to back down. Dorian, on the other hand, didn't know this boundary.

Dorian's childhood was marked by fears. He could hardly sleep alone at night. He had nightmares, and I often had to sit with him to calm him down. At the time, I thought it was just a phase, that he was perhaps just particularly sensitive. But as he got older, his anxiety didn't subside – it actually increased.

The turning point came on New Year's Eve when Dorian was 15 years old. After a party where he had drunk alcohol, he hit his head against a wardrobe. He never told me exactly what happened, but on New Year's Day he was completely changed. Suddenly he was like a little child again. He held my hand and was terrified. He didn't leave the house, spent most of his



time in bed and hardly spoke. And then, after a week, it was as if someone had flipped a switch – it was all over. It was as if nothing had happened.

But it wasn't just a one-off incident. Every month, almost to the day every 28 days, the pattern repeated itself: for a week he was a frightened teenager, then he seemed normal again. It was incomprehensible.

In February, during school holidays, my husband, Dorian and I went skiing like we did every year. We were there with friends and their children, and I hoped that the fresh air and exercise would do Dorian good. But on the very first day, he completely lost his orientation. He couldn't find his way back to the accommodation and we had to search for him. After that, he refused to continue skiing with the others. Instead, he stayed in the accommodation and didn't want us to leave. When my husband and I went for a walk, he panicked. 'What if something happens to you?' he kept asking. His fear was so great that it completely paralysed him.

After this incident, we consulted a doctor. Numerous examinations followed before a diagnosis was finally made: a cyst on the hippocampus that regularly filled with fluid and thus triggered his anxiety attacks. The doctors recommended surgery, and I clung to the hope that this could be the solution. But even after the operation, his condition did not improve. Instead, he began to withdraw even further. He became suspicious, sometimes appearing to live in a world that was invisible to us. Sometimes he would talk to someone that no one but him could see.

Over time, school became another struggle. He transferred from high school to business school, but even there he found no stability. He kept saying, 'I want to be independent, I want to take control of my life.' I didn't want to deny him that wish. So, I let him go. He moved to a city, away from the countryside, where we lived and where everyone talked about everyone. I hoped that he would be able to make a fresh start there.

But it soon became clear that he was moving further and further in the wrong direction. Sometimes he came home on weekends. Then I found a bong in his room, I didn't know exactly what he was consuming – but I sensed that I was losing control over him. I tried to set rules, to protect him. But I was too weak. I was afraid of losing him for good. I had a job, but my thoughts revolved only around him. I searched for answers, running from one doctor to the next, hoping for a solution. I constantly asked myself: 'What is this?' and 'How can we cure it?'

Then, at the age of 20, the diagnosis of schizophrenia arrived: When I heard the word for the first time, it was like a door that I had desperately kept open all these years slammed shut. I had been looking for a simple answer for so long, hoping that there was something that could be easily treated. But now it was clear: there was no quick way back, no cure that could undo everything fast.





But there was a way forward. The medication helped, even if it didn't always work perfectly. The therapies required patience, but they brought progress. And eventually, after many setbacks, a new life began to take shape for him – one that may have been different from the one I had once imagined, but no less valuable.

Today, Dorian lives in his own world – no longer in one that separates him from reality, but in one that he has built for himself. A life with structure, with people who understand him, with small steps that have led to big changes. He has learned to live with his illness instead of fighting against it.

Main topics covered in this story

Behaviour and disease manifestations of the son Dorian:

Psychotic symptoms; Inactivity/Blunting; Other psychopathological symptoms; Strange behaviour (not aggressive); Insight into illness/Compliance with therapy; Disease course

Experiences and emotions of the mother Daniela:

Distress; Care dilemma – more or less care and control; Appraisal of others; Positive attitudes of family member

Other main topics:

Employment, Education, Finances of family member and patient; Physical health of family member/patient; Services and Professionals; Therapy-related issues



7 Amelie - a mother caring for her son

Amelie is the 50-year-old mother of Thomas, who is now 20 years old and was diagnosed with schizophrenia one year ago. Amelie describes how, after a first acute episode in which Thomas put their flat into ruins, she is oscillating between controlling Thomas and "letting go". This dilemma is complicated by Thomas' cannabis use. (54 words)

"It's important for me to accept that I can't control everything"

In the first acute phase my son had to be treated in a psychiatric ward after a violent incident. This was an unimaginable shock for me as a mother. The fact that our flat was in ruins due to his complete loss of control was of secondary importance at that moment. Feelings of insecurity and fear spread through me like a thick fog that instantly obscures any clear view.

He had always been a sensitive young man, but over time his behaviour changed markedly. His meetings with his friends became less frequent, which, in retrospect, I was perhaps a little relieved about. I still remember the smell of cannabis in his hair and his red eyes every time he came home.

Gradually he became more withdrawn, began to perceive things that did not exist for others and developed severe anxiety. I didn't know how to deal with it at the time and was desperate for answers. Unfortunately, his condition continued to deteriorate and he had to be admitted to hospital. The diagnosis provided some explanation, but it also made us realise that our lives would never be the same again.

The situation is doubly stressful for me. On the one hand, it is difficult to see my son struggling with his illness. On the other hand, I feel the full weight of responsibility on my shoulders. I work and have many responsibilities, while trying to support him in any way I can. He lives with me and I often feel that I'm solely responsible for everything - his finances, his daily routine and making sure he gets the help he needs.

One of the biggest challenges remains his use of cannabis. He continues to use it even though it's bad for his mental health and have tried to talk to him about it, but I often meet resistance, like I'm talking to a brick wall. Sometimes it feels like I have to be constantly on guard to protect him - from himself and from circumstances that might make his illness worse.

I have learnt a lot about myself and my son's illness over the past few months. The support provided by counselling has helped me to understand the condition better and also to find a



way for myself to deal with the situation. But it's an ongoing struggle, especially as I sometimes feel overwhelmed myself. There are days when I wonder how much longer I can go on like this.

One ray of hope is that he is part of a programme that opens up social and professional prospects for him. I really hope this will help him to regain some independence. At the same time, it's important for me to accept that I can't control everything. I have to learn to let go - even if it's difficult. My biggest wish is that one day my son will be able to lead a stable and independent life. Until then, I will do my best to support him on his journey.

Main topics covered in this story

Behaviour and disease manifestations of the son Thomas:

*Psychotic symptoms; Inactivity/Blunting; Other psychopathological symptoms;
Aggressive behaviour; Disease course*

Experiences and emotions of the mother Amelie:

*Distress; Care dilemma – more or less care and control; Other challenges; Appraisal of others;
Positive attitudes of family member*

Other main topics:

Physical health of family member/patient; Services and Professionals; Information deficits



8 Ilse - a mother caring for her son

Ilse is the 68-year-old mother of Wolfgang, who was diagnosed with schizophrenia 11 years ago, when he was 29. Ilse cares for her son in their common flat and her story is rather gloomy, with Wolfgang being psychotic most of the time, accumulating debts and Ilse's health decreasing. Desperation and hopelessness prevail in this story. (55 words)

“Fear has taken over my life like an invisible, paralysing burden that I can no longer shake off”

The schizophrenia of my son Wolfgang was triggered by a long-term drug addiction. He is now on a substitution programme, but his condition is still not stable. He spends most of his time in his room, talking to himself because he hears voices and is completely isolated. He often claims that he needs to work, although in his world this has no relation to reality.

Sometimes he is in a good mood, but these phases are deceptive. As soon as he wants something, like cigarettes or sweets, and realises that he can't afford it, he gets angry, yells and sometimes becomes aggressive.

A few months ago, he stopped taking his depot injections, which I know are important for him. He doesn't manage to go to an appointment with the Public Employment Service, which would be necessary to be continuously insured with the public health insurance system. So I have to pay for the medication.

I am officially retired since the beginning of the year, but I work overtime to cover the costs of his care and our household. There is no support, no relief. My son is practically totally dependent on me and I often wonder how much longer I can go on like this.

The nights are the worst. My son is mostly nocturnal and any loud noise makes me jump up. I sit up in bed, my heart racing, wondering what will happen next. Fear has taken over my life like an invisible, paralysing burden that I can no longer shake off. What's more, in his delusions he sometimes believes in things that don't exist - like animals living under his skin. He often goes days without washing and his self-care is almost non-existent.



I have tried everything to get him help. I tried to get legal guardianship for him, but my son has fought that twice. Even the police know him because he has damaged property in a psychotic state. He has also been in and out of psychiatric wards, but nothing has really changed.

I am worried about what will happen to him. He has a child who lives in an institution with his mentally ill mother because neither of them is able to look after the child. My son does not pay child support and is in considerable debt. He does not open his mail and simply makes important letters disappear. I can no longer keep track of what is coming his way - creditors, authorities, appointments. It's a mess.

I am a trained nurse, but despite my expertise, I feel powerless. His mental illness is a burden I can no longer bear alone. I dream that he could move into a supported living facility where he would get the support he so desperately needs and where I would be relieved of the financial burden. But the reality is different.

I don't know how much longer I can do this. My own health is deteriorating, I now take blood pressure tablets every day. But what worries me most is what will happen to my son when I am no longer there. Who will look after him?

Main topics covered in this story

Behaviour and disease manifestations of the son Wolfgang:

Psychotic symptoms; Inactivity/Blunting; Other psychopathological symptoms; Strange behaviour (not aggressive); Aggressive behaviour; Insight into illness/Compliance with therapy

Experiences and emotions of the mother Ilse:

Distress; Other challenges

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Physical health of family member/patient; Services and Professionals; Therapy-related issues; Causal assumptions/theories; Legal issues and police involvement



9 Michael - a father caring for his son

Michael is the widowed 65-year-old father who cares for his son David, who was diagnosed with schizophrenia 6 years ago, when he was 24. They had ups and downs together over the years - David having worked part-time as an IT specialist, but also having committed a criminal act -, leaving the father constantly in sorrow and oscillating between protection and letting go. (63 words)

"It's hard for me to relinquish control, but I know I have to give him the space to make his own way"

My son David was diagnosed with schizophrenia 6 years ago. The first few years after the diagnosis were particularly difficult. He suffered repeatedly from severe psychotic episodes which led to several hospitalisations. Unfortunately, he was reluctant to undergo consistent treatment for a long time, which led to severe relapses. Since then, our life has had many ups and downs, and in recent years I have often felt that I have reached my limits.

During a particularly difficult phase of his illness, he even committed a criminal act, which almost resulted in him being admitted to a forensic psychiatric ward. It was a turning point when he finally received both medication and psychotherapy under a court order. Since then, he has been able to stabilise and it seemed that his condition was finally improving.

However, I am constantly worried about his future. He receives a half-orphan's pension after his mother's death, which gives him some security, and he currently works 15 hours a week in his job as an IT specialist. I know how important this work is to him - not only financially, but also for his self-esteem.

But when he told me recently that he felt overwhelmed and wanted to quit his job, I felt old fears rise up again. What worried me even more was that he was talking to his psychiatrist about reducing his medication. This news put me on high alert. I know only too well the consequences of such a decision. I have already noticed signs that remind me of previous episodes, i.e., moments when he withdraws into himself or talks about perceptions that are not real.

My worries and anxieties often won't let me go, and I notice how they put a strain on our relationship. I want to protect him, but sometimes I end up putting pressure on him with my



worries and advice - especially when it comes to taking his medication regularly. I try to encourage him to take advantage of therapy programmes and to make careful choices. But my son wants to take more responsibility for himself and wants to make his own decisions with his doctor. As a result, he is increasingly avoiding our conversations, which is widening the gap between us.

The memories of when he became a criminal weigh heavily on me. These experiences have narrowed my perspective and I am constantly afraid that something similar might happen again. It's as if I can't let go - I'm always afraid that we'll be thrown back into the same difficult phases.

The fact that he was granted the increased family allowance relatively quickly gave me a glimmer of hope, a bit of security - in case he was unable to work in the longer term. He decided to give up his job for the time being, which worried me at first. But it seems to be good for his health. His condition has improved and I hope that in time he will feel stable enough to return to the work he enjoys and is valued for.

Finding the balance between support and letting go remains a constant challenge for me as a father. It's hard for me to relinquish control, but I know I have to give him the space to make his own way.

Main topics covered in this story

Behaviour and disease manifestations of the son David:

Psychotic symptoms; Inactivity/Blunting; Insight into illness/Compliance with therapy;

Disease course

Experiences and emotions of the father Michael:

Care dilemma – more or less care and control; Other challenges

Other main topics:

Employment, Education, Finances of family member and patient; Services and Professionals; Therapy-related issues; Legal issues and police involvement



10 Luise - a mother caring for her daughter

Luise is the 50-year-old mother of Diana, who received a tentative diagnosis of schizophrenia two years ago at the young age of 16, but was never hospitalised. Luise describes that Diana lives completely withdrawn in her room, experiences hallucinations and delusions, and occasionally erupts into anger and shouting episodes, leaving Luise in despair and helplessness. (55 words)

"What weighs most heavily on me is her unpredictability"

I have reached a point where I just don't know what else to do. My daughter Diana has been receiving psychiatric and therapeutic treatment for some time, but progress has been slow. There are always periods when she withdraws a lot and is plagued by paranoid thoughts, which weigh heavily on her and have a significant impact on our lives.

She wanted to do an apprenticeship after school, started several programmes but didn't finish any of them and recently lost her job in a supermarket. Since then, she has been stuck at home. I see her withdrawing more and more into her room. She has almost no contact with anyone, hardly speaks to me or her father. I have the feeling that the outside world has become completely alien to her.

What weighs most heavily on me is her unpredictability. There are days when everything seems to be more or less okay. But then, often for seemingly trivial reasons, she erupts like a thunderstorm. She shouts, gets angry, slams doors. Soon her anger turns inward. She sinks into her own world of thoughts. Her reality is dominated by voices and images that are frighteningly real to her and plunge her into a state of fear and isolation. I don't know how to stop her. I don't even know if I can.

Over the last few weeks, she has told me about voices she claims to hear. She says these voices talk to her, sometimes even against her. It sounds like they're making her do things she doesn't want to do. It breaks my heart, but at the same time I don't know how to talk to her about it. I feel like I'm losing her more and more.

I wish she had something to hold on to. A job, a task, maybe even a routine. But I see how unstable she is and I wonder if that's even possible. At the same time, I feel guilty because



sometimes I just want some peace and quiet. A break from the outbursts, from the constant worrying, from the constant lurking.

We have been advised to consider hospitalisation. Maybe that would help her. But I'm afraid to let her go. Afraid that she will withdraw even more from us. And yet I know it can't go on like this. I have no more strength to live like this, but I also have no more strength to give her up. And that's where I am now - somewhere between fear and helplessness, between anger and despair. I just hope there is another way that will help both of us.

Main topics covered in this story

Behaviour and disease manifestations of the daughter Diana:

Psychotic symptoms; Inactivity/Blunting; Strange behaviour (not aggressive); Aggressive behaviour

Experiences and emotions of the mother Luise:

Distress; Care dilemma – more or less care and control; Appraisal of others

Other main topics:

Employment, Education, Finances of family member and patient; Services and Professionals; Information deficits



11 Karin - a mother caring for her daughter

Karin is 61 years old and the mother of her 31-year-old daughter Johanna, who was diagnosed with schizophrenia 7 years ago after having successfully completed a university degree. Even though Johanna has had several psychotic episodes with hospitalisation, Karin is still ambivalent about her daughter's diagnosis and treatment, and vividly describes her own doubts and confusion. (56 words)

"I wish I could organise my thoughts and find some direction"

There are days when I wonder how we got here. My daughter, who is highly gifted and has a degree in pharmacy, once had many plans and opportunities. Now she is 31 and we are back to square one. Over the past few years, schizophrenia has repeatedly fragmented her life, each time taking her a little further away from herself.

The fifth psychotic episode has just landed her back in hospital. This time she couldn't stay in her flat near her university. Too unstable, too dangerous, they told me. So, she's back at our parents' house, back in her old room, back in our care. And although I love her, although I want nothing more than for her to be well, I'm exhausted.

Our family has a small business. Work is a core value for us, it always has been. My other children have thrown themselves into the business with great dedication, taking on tasks and proving themselves. But my daughter doesn't fit into that world. She's different. She has always been the dreamer, the searcher. That was fine as long as she flourished in her studies, as long as she could shine with her visions and her thirst for knowledge. But that was a long time ago.

After her studies, she was unable to enter the profession. It was as if the idea of a career crushed her. So, she started something completely different: ethnology. It seemed like a fresh start, but then came the next relapse. Now she talks about wanting to be a nurse. I listen to her and nod, saying it's a good idea. But deep down I have doubts. Isn't this just another fragment of a life that can't be put back together?

I find it particularly difficult to accept the illness. I know she is ill and needs help. But part of me still hopes that one day she will just get up and leave all this behind. That she will no longer need the medication and will regain her independence. Maybe it's my fault that she keeps stopping her medication. I was never convinced it was the right approach. I can see that her



psychotherapy is helping her and I often wonder if there aren't other, gentler ways of supporting her.

Her illness is a taboo subject in the family. My other children look at her with a mixture of incomprehension and rejection. They only see that she contributes nothing, that she has no job, that she is often lost in her own thoughts. But they don't see what I see: the effort she makes every day.

I wish I could organise my thoughts and find some direction. But everything seems so unresolved. Will she ever be able to stand on her own two feet again? And if so, how? I can't carry the responsibility forever. But the thought of letting her go completely fills me with panic. She has dreams, I know. But the dreams always seem a little too big for the reality she lives in.

Sometimes I imagine what our lives would have been like if this illness had never happened. But those are dangerous thoughts. Because what was can't be brought back.

Main topics covered in this story

Behaviour and disease manifestations of the daughter Johanna:

Self-harm; Disease course

Experiences and emotions of the mother Karin:

Distress; Care dilemma – more or less care and control; Other challenges; Appraisal of others;

Patient moves out of/back to the family home

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Services and Professionals; Therapy-related issues; Causal assumptions/theories



12 Flora - a sister caring for her brother

Flora is 57 years old and has been caring for her elder brother Leopold since her teenage years. Leopold was diagnosed with schizophrenia 40 years ago, when he was 20. Flora has picked out a turbulent episode here, describing the dramatic events of a very long night, when her brother got lost after injuring people, was searched by the police and herself being full of fear that something terrible might happen. (71 words)

"My brother often felt persecuted and bugged, which eventually led him to persecute and harm others"

My brother, who gave himself many bizarre names, lived in a world of paranoid schizophrenia. His personality fluctuated between extroverted and introverted, depending on his medication. He often felt persecuted and bugged, which eventually led him to persecute and harm someone himself.

It was the middle of the night when the chaos broke out. I had just gone to bed to get a few hours' sleep when suddenly the phone rang. My older brother had gone missing again. This time he had not only hurt someone, but was on the run from the police. The incident was surreal, like something out of a film: he was convinced he was being chased by a Russian mafia gang. In his madness, he smashed a car window, injured a young man and shouted that he was going to kill everyone. In reality, he had attacked a couple of driving license novices who happened to be parked nearby.

The police were already involved, but I couldn't wait. I was in contact with three different police stations, hoping to find out where he was. At the same time, I searched the area, looking for the places I knew he would go if he was hiding. Woods, old buildings, the area around the railway tracks. All I could think about was finding him before he threw himself in front of a train. My brother was also the father of a little girl - three at the time - which made his situation even more tragic.

The hours dragged on and I knew I was putting myself in danger. But I didn't care. I was the one in the family who felt responsible - since I was a teenager. My parents had long since resigned themselves. My mum said she couldn't take it anymore, and my dad closed his eyes and pretended it wasn't happening. Of course, I still updated them on the situation from time to



time. I reassured them that whatever it was would end soon - and tried to maintain control as best I could.

Around seven o'clock in the morning, my phone rang. It was my brother. He sounded exhausted and scared, but he was talking to me. That in itself was a good sign. He was riding his bike right next to the railway tracks. I tried to stay calm and told him about his little daughter and how she still needed him. Something I said made him change his mind. He decided to turn himself in and rode his bike to the family doctor.

The police finally came to get him. Two officers, unarmed and sympathetic. They told me later how admirable they thought what I had done was. It was the first time that night that I was able to let go. I finally cried. I could finally breathe.

But that was only the beginning. My brother was stabilised and later transferred to a forensic unit. For me, it felt like a relief - he was finally in a place where he could no longer harm us or himself. At the same time, I was wracked with guilt. Had I abandoned him by leaving him in the care of others?

The stigma that followed was overwhelming. Newspapers reported the incident, but the articles were full of errors: wrong age, wrong place of residence, completely distorted stories. I was almost grateful for it, because it protected my parents from the truth. There were also comments circulating on social media, which I deleted as soon as I could to save us any more embarrassment.

That night, the longest of my life, was just one of many challenges. But it also showed me something important: I can fight, even when I'm scared. And even in the darkest moments, there is hope.

Main topics covered in this story

Behaviour and disease manifestations of the brother Leopold:

Psychotic symptoms; Strange behaviour (not aggressive); Aggressive behaviour; Self-harm

Experiences and emotions of the sister Flora:

Distress; Care dilemma – more or less care and control; Other challenges; Appraisal of others; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Services and Professionals; Stigma, Discrimination, Social network, Public realm; Legal issues and police involvement



13 Anja - a sister caring for her brother

Anja is the 40-year-old sister of her 3 years younger brother Karl, who was diagnosed with schizophrenia at the age of 17. She describes how her brother was threatening other members of the family and how she managed the dangerous situations because she knew her brother was trusting her. (49 words)

"We were torn between the desire to protect my brother and the fear of his actions"

I remember that my brother together with his friends had experimented for some time with angel's trumpets, a dangerous hallucinogen, before he developed his first episode with hallucinations and paranoia. Since then, he had several psychotic episodes when he also became aggressive. But he also had long periods, when he was calm. I will focus here on three dramatic episodes, where I was involved.

First, I have to say that our family could not cope with his illness. My mother became more and more withdrawn. I once heard her say to a neighbour: "The doctors end up blaming the mothers anyway. I don't want to hear it anymore." My father? He pretended the problem didn't exist. 'It doesn't happen here,' he said. 'You only see it on TV.' So, it came that I felt responsible and tried to help, whenever help was needed, especially during the first years of his disease.

Once, when my brother was going through a psychotic phase, he suddenly appeared in front of our house. He had a machete in his hand. My partner at the time was there and was about to leave the house, but my brother was standing in the doorway staring at him. The tension was palpable, like a thunderstorm that could break out any moment. I acted instinctively. I sat down on my partner's lap, held him tight and spoke softly to my brother: "You are not safe here," I said, "please leave now". After a few minutes he did leave. My heart was pounding, but I knew the danger wasn't over.

I called the police. But when I explained what had happened, I was given an evasive answer: "If he tries to break into the house again, please contact us again". It was clear that I was on my own.

Another time, the situation escalated even more dramatically. My brother was delusional again and after a dispute with our other brother Max in front of our house where I was present tried



to overrun Max with a car. I knew he would never do anything to me. So, without thinking, I stood in front of the car and forced him to stop. And it ended well. But even then, we knew the police wouldn't be of much help. We didn't even call them because nobody had been hurt. That was the logic we lived with.

Those moments of self-administered justice left their mark. Not only on me, but on the whole family. We were torn between the desire to protect my brother and the fear of his actions.

But the darkest moments were not the violent ones, but the desperate ones. I remember visiting him once at his home. He had just taken some medication and was calm, almost apathetic. But I sensed something was wrong.

He had prepared a rope to take his own life. He was crying, screaming, saying he couldn't take it anymore. I didn't know what to do. If I had called the police, he would have hated me. Instead, I promised him we would find a way if he just gave me the rope. He let me take it. I went home and cried all night. Part of me thought at the time, 'Maybe he should just do it, then we'll all be at peace.' That thought still haunts me, but I know it came from sheer exhaustion.

My brother spent many years caught between anger, madness and periods of clarity. I was exhausted and it took me a long time to find support - far too long. He is better now. He has calmed down and I still visit him from time to time and he enjoys my visits. It's hard to say how I got through it all. Maybe because I had to. There was no other way.

Main topics covered in this story

Behaviour and disease manifestations of the brother Karl:

Psychotic symptoms; Aggressive behaviour; Self-harm

Experiences and emotions of the sister Anja:

Distress; Other challenges; Appraisal of others; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Therapy-related issues



14 Carola - a sister caring for her brother

Carola is the 58-year-old sister of Markus, actually 64 years old, who was diagnosed with schizophrenia 36 years ago, when he was 28. Carola has been accompanying her brother the whole life and tells us about legal and financial problems she has encountered in the health care system, and also the help she received from attending counselling sessions of a family self-help organisation. (63 words)

“I have learnt that even the smallest progress is valuable. And that's what keeps me going”

I remember the day I was sitting again in the waiting room of the health insurance office. I had taken on the difficult task of organising health insurance for my brother who hadn't been able to think clearly for years because his world was dominated by voices and visions.

My brother no longer had health insurance - a decision he had made in the midst of his psychosis. He believed he was enlightened, protected by higher powers and free from the constraints of this world. "I don't need anyone," he often said. But when one day he could no longer walk, I was faced with a seemingly impossible task. The bureaucracy seemed insurmountable: Forms, documents, certificates - I could hardly understand what was being asked of me. I was so exhausted that I could barely hear what the officials were saying. Every step took forever and felt like a drop in the ocean.

Another pain point was the health care system itself. Doctors and staff were often helpful, but their hands were tied. No one was allowed to speak to me without my brother's express permission. He often told the doctors a different story than he told me. It was years before I was able to understand, with the help of medical records, what had actually happened.

This lack of communication was crippling. I didn't know what the options were, what help might have been available or what my rights were as a family member. All of this could have eased the pressure, but instead the burden grew with each new hurdle.

Fear was my constant companion. It crept into my nights and held me in its grip during the day. I was particularly tormented by the uncertainty of the future. My mind was constantly inventing scenarios in order to be prepared, but these fantasies were mostly dark and paralysed me more than they helped. At the same time, I felt trapped in an endless cycle. As long as my brother didn't acknowledge that he was ill, nothing would change. He clung to the belief that he just



had ADHD and refused to take the necessary medication. The depot injection was the only small success I was able to achieve.

A counsellor at a self-help family organisation, which came into our lives far too late, finally showed me that I wasn't the only one carrying such burdens. It was a relief to know that there were others in similar situations. But at the time it still felt too far away. I wished for more understanding from the family - especially that they would at least try to understand what it was like to struggle day after day without being able to achieve anything. The lack of education in the family about my brother's illness only made the situation more difficult for everyone. They didn't want to understand. They couldn't understand.

What helped me in the end was not just the exchange with other family members, but the fact that at some point I started to look after myself. I had to realise that I had to set my own limits, otherwise I wouldn't survive. The journey is still difficult, but I can see glimmers of hope. There is still a lot of work to be done - for my brother, for me and for the system that often leaves people like him alone. But I have learnt that even the smallest progress is valuable. And that's what keeps me going.

Main topics covered in this story

Behaviour and disease manifestations of the brother Markus:

Psychotic symptoms; Disorganised/Incoherent behaviour; Insight into illness/Compliance with therapy

Experiences and emotions of the sister Carola:

Distress; Other challenges; Appraisal of others; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Physical health of family member/patient; Therapy-related issues; Legal issues and police involvement



15 Tanja - a mother caring for her son

Tanja is the 64-year-old mother of Stefan, who was diagnosed with schizophrenia 24 years ago, when he was 21. Tanja describes her painful, but finally successful attempts to find a protective living situation for Stefan outside the family home and laments the discrimination experiences of her son with public services. (50 words)

"The rest of the family couldn't deal with his loitering behaviour and diagnosed him as lazy rather than ill"

My son had an unremarkable education, had been working already for two years and was living with his girlfriend when he had a breakdown and was diagnosed with paranoid schizophrenia at the age of 21. He moved back to our family home. Ever since then it has been impossible for him to lead a normal life.

Living together was very difficult. My son's greatest wish was to stand on his own feet, to work and live independently, but he was unable to support himself. Our aim was therefore to help him lead an independent life outside of our home. But several attempts to find him a small flat or a room failed. When he kept returning to us after a few days or weeks, we tried to find him a supported residential facility which was particularly challenging.

He was invited to an interview, where a potential admission to a residential facility was to be decided. However, an unexpected setback occurred during this interview. Stefan was accused of being a drug addict and was therefore rejected. Although he had experimented with various drugs - both legal and illegal - there was no question of addiction. It was more a case of trying to cope with his mental health problems on his own, because he didn't want to accept his illness as such. Also, the staff carrying out the interview did not sufficiently understand his fears of change and the uncertainties of moving to a new environment. This refusal was a hard blow for us parents.

Even more than the failed housing attempts, he was experiencing setbacks in his attempts to return to work or other activities, which ended after a few days or weeks. His mental strain made this impossible.

He also had financial problems. His income consisted of alternating sickness and unemployment benefits. There were always a few weeks in between when he had no income at all because he



was unable to go to the Public Employment Service and the Health Insurance Fund. Unfortunately, the staff there (not everyone) interpreted his illness-related 'inability' as 'unwillingness'. I supported him as best I could, often accompanied him and helped him with the bureaucracy there. But I also wanted him to take responsibility, which often led to conflicts.

There were always hospital stays when things got out of hand because he didn't take his medication. In those cases, he was completely non-compliant and would only take his medication when we urged him to - so that he would still have a roof over his head.

Another attempt to enable him to live outside our home was to live with his grandparents. His grandmother took great care of him and even found him a job nearby. However, he soon became overwhelmed and would spend days in bed, not taking his medication and becoming completely withdrawn.

His behaviour also led to conflicts with the rest of the family in the house. Of course, they didn't agree with this loitering behaviour. They couldn't deal with it and diagnosed him as lazy rather than ill. Our son was the cause of a major generational dispute. A psychotic phase followed and we had to take him back home. So the „second family solution“ also failed.

Returning to us felt like a step backwards, but it was the only way to protect him from further escalation. However, moving back in was the turning point we hadn't expected. In the end, our joint search led to a long-term solution that gave him stability and independence. He now lives in an assisted living facility, is proud of his progress and visits us regularly. Our relationship is as good as it has ever been and we look to the future with confidence.

Main topics covered in this story

Behaviour and disease manifestations of the son Stefan:

Psychotic symptoms; Inactivity/Blunting; Insight into illness/Compliance with therapy; Being stressed by external factors

Experiences and emotions of the mother Tanja:

Care dilemma – more or less care and control; Appraisal of others; Positive attitudes of family member; Patient moves out of/back to the family home

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Physical health of family member/patient; Services and Professionals; Therapy-related issues; Stigma, Discrimination, Social network, Public realm



16 Lotta - a mother caring for her son

Lotta is the 67-year-old mother of Jacob, who is 41 years old and was diagnosed with schizophrenia at the age of 22. Lotta vividly describes Jacob's violent episodes, which alternated with periods of calm, and how her joining a family self-help organisation has helped her and her son to finally accept the illness and not fight it in an exhausting way. (61 words)

"During all these times, I never stopped hoping and believing that things would turn around"

There were times when we hardly knew how to go on as a family. Our son, usually so peace-loving, kept getting into explosive conflicts that shook us to the core. One time, an argument escalated to the point where he and his father were rolling around on the floor, screaming and fighting - a scene I could never have imagined. The trigger? My husband was working on the computer and our son had been bothering him for so long that his nerves were frayed. From then on, my husband became enemy number one.

I will never forget another episode. A trivial argument in the kitchen ended with our son smashing an empty bottle and threatening his father with the broken glass. He then stormed into the car and drove off in a rage. From that point on, we no longer felt safe in our own home. We started locking our bedroom door at night - a frightening symbol of how much the disease had taken over our lives.

The disease manifested itself in many ways. For one thing, there were constant accusations. Our son accused us of having given him insurmountable deficits in his childhood. At the same time, he blamed himself for misfortunes that had nothing to do with him, such as his godmother's inability to have children.

From time to time there were good periods, moments when life together seemed almost normal. But these were usually linked to the quality of his sleep. When this was disturbed, he would fall into a deep depression, lying in bed for days with all his clothes and heavy shoes on, unable to cope with simple tasks such as changing the sheets. I tried to help him, step by step: a pillowcase today, the duvet tomorrow. But even that was sometimes too much.

In between, there were nights I couldn't bear. I would hear him stomping around upstairs, talking - not to us, but to himself, or to the voices that tormented him. He wouldn't open the



door, so I went outside and stood further away from the house to look in through the open curtains. He kept pacing, going to the mirror and grimacing.

Finally, I knocked on his door so hard that he had to open it. I confronted him and told him that if he didn't start taking his medication as prescribed immediately, he would have to move out. He hastily swallowed a handful of pills. There was an hour of silence. Then he rushed into our bedroom, rolled around on the floor, vomited and vomited - a terrifying state.

The emergency doctor and paramedics arrived and he was taken to a distant hospital. I went with him, of course. The preliminary diagnosis was „panic attack“. He was asleep. I sat in the waiting room all night with sleep-deprived patients, listening to life stories that took my breath away. There were fantasy worlds that seemed familiar and also amused me. My supply of cigarettes ran out very quickly because everyone was using them.

In the morning, when my son had had a good night's rest, he had a doctor's appointment. He told the doctor that he had eaten cow dung mushrooms yesterday, which had triggered the attack. But there were no cow dung mushrooms this time of year, and my son hadn't been out of the house for days.

Typical - he always found an explanation, whether it was someone else's fault or his own, just so he didn't have to admit he was ill. He didn't want to be! So now everything was fine, he was well rested and didn't want to stay in hospital. He wanted to go home. My husband had to pick us up - and it was Mother's Day.

During all these times, I never stopped hoping and believing that things would turn around. When he would be ready to accept the therapies, when he would find the right people to trust in the support system that I had come to know better thanks to the family self-help organisation I joined. I myself have grown in this role. The valuable exchange with other relatives and the lectures and training sessions have strengthened me. I knew that you can practice calmness, that calmness and confidence don't mean looking away and developing a feeling of sourness.

Now, after so many years, I am still learning and have the good feeling that I still have a trump card up my sleeve, that I can still learn something new and helpful. In the meantime, our son and we as a family have learnt to deal well with the disease of schizophrenia, to accept it and not to fight it in an exhausting way. Good things take time!

Main topics covered in this story





Behaviour and disease manifestations of the son Jacob:

Psychotic symptoms; Inactivity/Blunting; Other psychopathological symptoms; Strange behaviour (not aggressive); Aggressive behaviour; Self-harm; Blaming; Insight into illness/Compliance with therapy; Disease course

Experiences and emotions of the mother Lotta:

Distress; Care dilemma – more or less care and control; Other challenges; Appraisal of others; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Physical health of family member/patient; Services and Professionals; Therapy-related issues; Causal assumptions/theories



17 Elisabeth - a mother caring for her son

Elisabeth is the 66-year-old mother of Peter, who was diagnosed with schizophrenia 25 years ago, when he was 19, and had already a job and a girlfriend. She describes how everyone in the family tried to help without realising that Peter was mentally ill, and how, after some time only, a psychiatrist gained his trust and Peter began to recognise his symptoms and agreed to take medication. (67 words)

“Should I have acted earlier?”

Before he received the diagnosis of schizophrenia, my son Peter had felt burnt out and overwhelmed. He was working at that time, when he started to blame himself for everything that went wrong in the company, even though his bosses were sympathetic and contradicted him. They helped him for several months, for example by allowing him to start work at noon, because he suffered from severe insomnia and could only sleep in the morning.

I assume that the fact that his ex-girlfriend, who was sitting in the same office and was about to get married, contributed to his difficult situation. Looking back, I wonder why, as his mother, I didn't push him to see a doctor, but was actually very happy that he left work of his own accord. A friend encouraged him to go to South America for a few months to work on a social project. It didn't work out because his insomnia didn't get any better, on the contrary.

His sister tried to help all of us. We were worried, and our son didn't accept any well-intentioned suggestions. She took him to the city where she was studying and a room was available in a shared flat. We parents could finally breathe a sigh of relief, he would have some distance from everything and there would also be a good opportunity for the professional training he would need for his planned stay in South America.

Three weeks later, however, our daughter brought him back exasperated. She and her flatmates had worked through the night to talk to him, encourage him and help him. In the process, they had neglected and overworked themselves and were unable to study for the upcoming exams.

Back home, he fell into a deep depression. Talking didn't help. "I don't know what to do," was the only thing he would say. We parents didn't realise that he was suffering from a serious



mental illness. He was very resistant to medical help. He was also reluctant to register as unemployed with the Public Employment Service.

He didn't attend appointments with psychologists that I had arranged. Once he said I should go myself - which I did. It was the first time I had ever been given detailed information about mental illness. At the same time, I was plagued by feelings of guilt - was it my fault as a mother? Should I have acted earlier?

Looking back, it was clear that he had suffered from hallucinations before. A trustworthy psychiatrist was later a key to bringing him out of his isolation. She gained his trust through patience and dialogue. This phase brought relief. He began to recognise his symptoms and agreed to take medication.

Also, I went for advice to family self-help organisation and learned how to cope with the disease through workshops and support groups. These networks gave the whole family strength and confidence.

Over time, our son slowly stabilised. It was a rocky road with setbacks, but also small successes that gave us hope. He became interested in creative activities, took part in supervised activities at a day centre and made friends. His schizophrenia remained a challenge, but he was learning to cope better. As a family we have grown from this experience.

Today, our son lives independently in a supported living facility, works part-time in a workshop and has made friends. It has been a long journey, but we have all learned to live with schizophrenia and find new hope.

Main topics covered in this story

Behaviour and disease manifestations of the son Peter:

Psychotic symptoms; Other psychopathological symptoms; Blaming; Insight into illness/Compliance with therapy; Being stressed by external factors; Disease course

Experiences and emotions of the mother Elisabeth:

Distress; Appraisal of others; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Services and Professionals; Therapy-related issues; Information deficits; Stigma, Discrimination, Social network, Public realm



18 Julia - a mother caring for her son

Julia is the 64-year-old mother of Ferdinand, who is now 42 and was diagnosed with paranoid schizophrenia at the age of 19. Julia describes the long period of uncertainty when the family couldn't make sense of Ferdinand's altered behaviour and writes in much detail about their struggle to help him, before it became clear that he suffered from a severe mental illness. (62 words)

“In reality, we simply had no idea and no experience of mental illness“

I will focus here on the difficult time, when we first realised that something was wrong with my son Ferdinand two decades ago and couldn't make sense of it.

At the time Ferdinand was living with his best friend and had a job. When he suddenly lost his job, he became depressed, was overtired and plagued by feelings of guilt. Sleepless nights and a deep lack of motivation weighed on him. "I can't do this anymore," he said as he resigned and moved back to our home. We parents tried everything without knowing how to really help. His condition got worse and worse and finally he spent all his time in bed, isolated and unreachable to us.

Cautious, unsuccessful attempts to seek medical help - we tried many things. Registering as unemployed? Fine, because it was necessary. Go to the doctor and get a sick note? Never! What was the point? He wasn't ill, only the people around him were.

There were still no alarm bells ringing for us parents that a serious mental illness might be at play. Our son was an adult, he had managed his life well so far and had been a peace- and harmony-loving person. We almost felt presumptuous to patronise him in this way.

To our surprise the depression seemed to improve slowly, without treatment. We thought he would blossom again. However, we then realised that he always used the car in the neighbourhood, even for very short distances. When we asked him about this, he said that he didn't want to walk because everyone in the neighbourhood was lurking behind the windows watching him. A visit to the bank was bad for him - he was asked his name, even though everyone in the village knew everyone else.

Slowly I began to realise that Ferdinand might suffer from a severe mental illness and I began to search the Internet, which made me feel insecure again. Twenty years ago, it was still difficult to find and filter the right web sites. I had new feelings of guilt with all the things I was reading - so much had gone wrong with us prenatally and I had fed my child all the wrong things, etc.



Then, we could often hear him talking to someone in his room and I thought he was on the phone - I was glad he still had contact with the outside world, since I had assumed that all his friends had disappeared. However, I had to realise that he was talking to voices!

You want to treat your grown-up son with respect and not always control him or pester him with stupid questions. But my husband, his father, sometimes confronted him with everyday things that made living together difficult. Mundane things like turning off the light, locking the front door, or what annoyed me too: not eating the food I had cooked, but eating later from the fridge.

The fact that he no longer wanted to sit with us for meals was almost fine with us - since no matter what topic was brought up at the table, it always ended in an argument and he would take his plate and leave. The tensions and conflicts increased and we often didn't know what to do next. It remained a constant challenge to find a way to deal with the situation.

Fast forward: Years later, when he had already been hospitalised several times, I came across a pile of medical reports from the hospital and realised a few things: that even in adolescence, he had sometimes felt that his thoughts were very different - split in two, with hallucinations, and that he had already been taking drugs.

Already before he had lost his job, he was undergoing all sorts of alternative treatments. He had reported his hallucinations to a psychiatrist he trusted, who probably had extraordinary talent and enough time to delve into his mind with him for some time. Unfortunately, she left the hospital and Ferdinand had no therapeutic contact anymore when he lost his job.

Main topics covered in this story

Behaviour and disease manifestations of the son Ferdinand:

Psychotic symptoms; Disorganised/Incoherent behaviour; Inactivity/Blunting; Other psychopathological symptoms; Insight into illness/Compliance with therapy; Disease course

Experiences and emotions of the mother Julia:

Distress; Care dilemma - more or less care and control; PDS moves out of/back to the family home

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Physical health of family member/patient; Services and Professionals; Information deficits



19 Bernadette - a mother caring for her son

Bernadette is the 57-year-old mother of 35-year-old Robin, who was diagnosed with schizophrenia at the age of 20. Bernadette focuses on the many frustrating years of trying to find an appropriate supported living facility for Robin which was finally successful and is regarded by Bernadette as the most important factor for the most satisfying situation today.

(56 words)

“Robin visits us regularly and our relationship is better than ever”

After receiving the diagnosis of schizophrenia, my son Robin who had lived already in a separate flat came back to live with us. Afterwards, attempts to move into a flat of his own were unsuccessful. Whether it was the fear of being alone, challenges of everyday life or a lack of sense of personal responsibility, he always returned to our home after a few days. This led to conflict and tension as living together became increasingly difficult.

We therefore tried to let Robin live with other relatives which failed. Then we sought help from mental health services. We tried everything, finding supported accommodation and accompanied him to job interviews. We often experienced rejection, one reason being that his problems were not seen as illness-related, but as laziness or a lack of discipline. These hurdles were painful, we didn't know what to do. It was a gruelling cycle of hope and frustration.

A turning point was, when he was admitted to the psychiatric department of our district hospital. Whereas in other hospitals we often felt that we were not taken seriously as relatives, here the opposite was true. My son built up a deep trust in one of the doctors, which was a crucial step for him. Gradually, he even allowed me to be present during consultations. Eventually, he agreed to let me talk to the doctor alone.

These discussions opened my eyes to many aspects of the disease that I hadn't understood before. Being involved in the treatment plans also helped me to cope with the challenges at home. This experience was a great relief for all of us.

Still, the biggest challenge remained, namely finding a long-term accommodation solution. After several attempts had failed, either due to Robin's fear of change or lack of therapeutic support, we were lucky that we got the information on an "intensively supported living facility" in a neighbouring district. This facility offered the structure and support he needed.



We applied for a place there, but had to wait several months. The preparation for moving in was as complex as it was nerve-racking. Fortunately, a dedicated psychologist worked with Robin during this time. She helped him to overcome his fears and slowly develop confidence in the new situation. Her commitment made all the difference because she knew how to deal with his insecurities.

Although there were setbacks - Robin deliberately tried to break the house rules during a trial stay in order to be rejected - the staff at the facility recognised that his defensive attitude was mainly due to fear. Eventually they gave him the chance he needed.

Now my son is still living there. The tight structure and ongoing support has helped him find stability. There have been no hospital admissions since. He is particularly proud to say: "I've moved away from home".

The stresses and strains of the past have characterised our family life for a long time, but many things have eased now. He visits us regularly and our relationship is better than ever. It has been a long road with many detours, but in the end, it has become clear that every experience has brought us further. Today we can say: all's well that ends well.

Main topics covered in this story

Behaviour and disease manifestations of the son Robin:

Disorganised/Incoherent behaviour; Other psychopathological symptoms; Disease course

Experiences and emotions of the mother Bernadette:

Distress; Appraisal of others; Positive attitudes of family member; Patient moves out of/back to the family home

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Services and Professionals; Information deficits; Stigma, Discrimination, Social network, Public realm





20 Sigrid - a mother caring for her daughter

Sigrid is the 58-year-old mother of Nicole, who is now 30 years old and was diagnosed with schizophrenia when she was 19. Sigrid describes how, after many years of stability due to treatment, a couple of years ago several psychotic episodes occurred, alternating with phases of stability leaving herself in a state of constant worry. (55 words)

"It's a fine line we're walking and I'm afraid of stumbling"

After having received the diagnosis of schizophrenia more than ten years ago, my daughter Nicole had a relatively stable period for many years, when she worked as a stone sculptor, a job she had received training for and liked very much.

The last few years, however, have been a rollercoaster ride of hope and despair. She was going through a period of severe psychotic episodes where she heard voices trying to control her and had delusions that frightened her deeply.

Finally, a year ago, with a lot of patience, medical support and, above all, her father and I pulling together despite our separation, we managed to get her back to work, into an organised life, and stability seemed to be returning.

But even during this period of equilibrium, I could always see small signs that worried me. I remember her saying once: "Mum, I love my job, but sometimes I feel like the stones are crushing me". She was talking about the harsh atmosphere in the stone sculpture workshop, a man's world that often left her alone with her insecurities. But she held out. She is incredibly strong - stronger than I ever was. But that's what scares me a lot: that she thinks she has to be strong all the time, even when she needs help.

Eight months ago, she started a relationship, something I wanted so much for her. At first, she was happy, almost as radiant as before, but lately there has been more and more tension. She told me about arguments where she felt her partner didn't understand her. And Nicole, who so often tries to please everyone, seemed to be losing herself in this relationship. This mixture of professional overload and emotional pressure worried me.

Slowly, changes in her behaviour began that made me prick up my ears. I realised that she started staying up at night, wandering around in her flat and talking to herself. She no longer sounded like my daughter, but like a distorted version of herself - hyper, but also agitated and unfocused. When I asked her if she was OK, she just shrugged it off: "Mum, don't worry. It's just stress." But I knew it was more than that. I could see the shadows under her eyes and the





nervousness in her movements. She spoke faster than I could follow, and her eyes lit up in a way that made me more worried than happy.

Her father saw things differently. "She needs to work it out for herself," he said. "The more we interfere, the worse it will get." His approach has always been different from mine. He believes that clear messages and a certain amount of firmness are best for her. "Nicole has to learn to live with the consequences of her actions," is one of his standard phrases. I understand that he wants to strengthen her, but I can't help but worry.

I wonder if I'm to blame for her fragility. I often think about our history together. We haven't had an easy time as a family. The separation from her father was hard for her, and although we were both always there for her, the question remains: Could we have done more? Could we have protected her better?

In our current difficult situation, I often feel torn. I want to give her autonomy - she's an adult - but I also see the signs of relapse and know she needs help. A crisis plan that her therapist once suggested would be so valuable now, but she didn't want to know about it at the time. She felt healthy and had stopped all treatment. Now I am again faced with the question of how to help her without patronising her or losing her.

I have shared these thoughts with her father during psychological counselling sessions. Despite our differences, we stand firmly by our daughter. Her illness often overwhelms us, but we know we are stronger together. After long discussions, we are now supporting her in giving up her work as a stone sculptor and find something different. It was clear that the strain was becoming too much.

Meanwhile, my nights are full of worry again. I think about how we can get her back into treatment without her feeling that we are trying to control her. I think about the counselling sessions that have shown me time and again that calm and trust are just as important as care and support. It's a fine line we're walking and I'm afraid of stumbling. But I know that we will walk it together as a family, through the ups and downs.

Main topics covered in this story

Behaviour and disease manifestations of the daughter Nicole:

Psychotic symptoms; Disorganised/Incoherent behaviour; Other psychopathological symptoms; Strange behaviour (not aggressive); Insight into illness/Compliance with therapy; Being stressed by external factors; Disease course

Experiences and emotions of the mother Sigrid:





Stories of Care

Navigating mental illness together

Distress; Care dilemma – more or less care and control; Appraisal of others; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Therapy-related issues; Causal assumptions/theories





21 Raluca - a mother caring for her daughter

Raluca, who lives in Romania, is the 62-year-old mother of Elena, who lives and works in Vienna and was diagnosed with schizoaffective psychosis 4 years ago at the age of 22. Raluca travelled to Vienna when her daughter was hospitalised on a psychiatric ward. Raluca describes her dilemma of staying in Vienna for a prolonged time or not to assist her daughter. (62 words)

"I understood that her desire to do it alone was part of her healing"

I live in Romania, my daughter Elena lives and works in Vienna and I came to Vienna to assist her when she was diagnosed with a psychotic disorder four years ago.

When I arrived in Vienna, everything was strange. Not only the city, which I hardly knew, but also the situation, which plunged me into a chaos of uncertainty. My daughter Elena, who had always been full of life and energy, was suddenly in a psychiatric hospital. I stood helplessly by her side, not knowing how to help her or what else to do.

She is my only daughter and I had no choice: I had to be there for her and had to leave my daily life in Romania. When I stood in front of her, I hardly recognised her. She seemed lost, trapped in a darkness from which I couldn't pull her out.

The doctors told me she was suffering from a psychotic disorder. Her symptoms were frightening and often surreal. She was convinced that she was caught in a web of conspiracies that was becoming increasingly tighter around her. Even everyday objects such as mirrors or televisions became instruments of surveillance in her eyes. She felt that her thoughts were no longer her own, but were being controlled by someone or something.

The first few weeks in Vienna I was completely overwhelmed. I didn't know anyone, felt like a stranger and didn't know how to support her. I spent hours in the hospital and was always with her. But the more I tried to help her, the more the question arose: was I too present or too withdrawn? Should I urge her to stay in hospital, as the doctors recommended, or should I respect her wish to go home?

As time went on, I became painfully aware that I too was reaching my limits. The nights without sleep, the constant feeling of exhaustion, the physical weakness that paralysed me - it was all dragging me down. It wasn't just the worries about Elena that weighed on me. Every night was a struggle against my own fears and doubts. I would lie awake for hours, listening to every sound, whether it was a sign from Elena or just the silence of the night. My body rebelled against the constant tension, my hands trembled with fatigue and my heart felt heavy.





Finally, after weeks of ups and downs, my daughter began to take steps in the right direction. She started talking again about the work she loved and began to make plans. It was as if she was slowly coming out of the darkness. But then came the moment I was dreading: Elena said she wanted to try it on her own. Without my constant support.

At first I was insecure, afraid of losing her if I withdrew. But I understood that her desire to do it alone was part of her healing. I stayed for a few days to make sure she was coping, and then I went back to Romania.

We spoke on the phone from time to time, but less and less often. Today, Elena is back to work, on a part-time basis so as not to strain herself. But although she is back to work, she often seems tired and overwhelmed. I can still see the shadows of the past in her eyes, which haven't completely disappeared. There are moments when I admire her strength, but also moments when I worry whether she is on the right track.

Sometimes, in quiet moments, I wonder if I left too soon. If my support would have been necessary for a longer time.

Main topics covered in this story

Behaviour and disease manifestations of the daughter Elena:

Psychotic symptoms; Disorganised/Incoherent behaviour; Inactivity/Blunting; Disease course

Experiences and emotions of the mother Raluca:

Distress; Care dilemma – more or less care and control; Appraisal of others

Other main topics:

Employment, Education, Finances of family member and patient; Services and Professionals



22 Helga - a mother caring for her son

Helga is the 70-year-old mother of Lukas, who had a first psychotic episode 20 years ago when he was 19. Helga describes how Lukas accepted medication which worked well for many years, before a severe relapse occurred, which again was overcome because Lukas finally accepted the illness and the treatment. (50 words)

"He had insight about his illness from the beginning and still so today"

My son Lukas had an inconspicuous childhood and adolescence. After primary and grammar school he graduated at a technical higher-level school. Instead of joining the army he worked in an alternative civilian service for people with mental disabilities. It was during this time that his illness broke out.

Lukas suddenly told me that he heard voices at night which scared him and disturbed his sleep. Fortunately, thanks to the quick intervention of our GP, we were able to get an appointment with a specialist we knew. With the help of medication, we were able to avoid a stay on a psychiatric ward.

After a long period of sick leave and continuous medication, our son had no problems for many years. We trusted the specialist's statement that it would be a one-time event.

But then came Easter 2014, when our son had been living with his then girlfriend for almost a year and his contact with us was rather loose. During his visit at Easter, we as relatives (parents and brother) noticed very disturbed and strange behaviour. It happened very quickly and on Easter Sunday I had to arrange for Lukas to be admitted to a psychiatric hospital with a severe psychosis.

This was the beginning of a difficult period for all of us. One positive thing I noticed in the hospital was the constructive attitude of the doctors and their conversations with us relatives. However, I must emphasise that our son, thank God, also trusted us and always wanted us to be involved in the discussions. He was diagnosed with schizophrenia. Six months later he ended his relationship and moved back in with us.

This was the beginning of a different life for all of us. Living together was not always easy and often led to conflicts. Respecting each other's boundaries was a particular challenge.

There was also the question of how to deal with our extended family and friends. I often had to endure painful comments from insensitive relatives, such as "You weren't tough and consistent enough" or "I have well-behaved children". There were also recriminations between my



husband and me. Statements like: "Your brother... your mother... behaves like our son, that's why he has this mental illness", often led to arguments.

Fortunately, I found out that a self-help organisation for families with such problems existed and I went there. Listening to the experiences of other relatives helped me a lot to learn how to deal with all this. I also quickly learned to be open about our situation, to tell others about it and got involved in the organisation in order to raise awareness and acceptance of mental illness in society.

What I think works well between my son and me is that we have always been able to talk to each other very well. I'm sure this is due to the deep and stable trust that exists between us. Also, he had insight about his illness from the beginning and has it still today. I often hear from other relatives that this makes the relationship immensely easier and how difficult it can be when this understanding is lacking.

In the meantime, my son has taken a very different professional career path. Originally from a technical background, he is now working in the social sector. He has now been studying social work for a few years and I can see how fulfilling it is for him in contrast to the time before, when he had had a lot of different jobs. Every time a job ended, I used to think: "Oh God, why can't it last?" But now I've learned to trust that he'll find his way - and that he'll keep going.

Main topics covered in this story

Behaviour and disease manifestations of the son Lukas:

Psychotic symptoms; Strange behaviour (not aggressive); Insight into illness/Compliance with therapy; Disease course

Experiences and emotions of the mother Helga:

Care dilemma – more or less care and control; Appraisal of others; Positive attitudes of family member; PDS moves out of/back to the family home

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Services and Professionals; Therapy-related issues; Causal assumptions/theories; Stigma, Discrimination, Social network, Public realm





23 Ulrike - a mother caring for her daughter

Ulrike is the 57-year-old mother of Paulina, who was diagnosed with schizophrenia 2 years ago at the age of 23, when she was hospitalised with an acute episode. Ulrike describes how, with the help of counselling at a family self-help organisation she found the adequate balance between protection and letting go. (51 words)

"I have learned that sometimes it is enough just to be there and trust that she will find her way"

I remember the afternoon I went to the family self-help organisation for the first time. It was a sunny day, but there was nothing but darkness and worry inside me. My daughter Paulina, just 23 years old, had been admitted to a psychiatric hospital. The doctors had talked about a psychosis. I couldn't believe it.

It had all started with her PhD. She was determined to finish it in record time. For weeks, all I saw of her were her books and her laptop. It was as if she had shut out the world around her. The pressure she was under was enormous, but she didn't want to show it to anyone. Instead, she withdrew more and more. Her nights got shorter, her coffee stronger, and at some point, I felt she was living in a bubble of tension and sleep deprivation.

Then Paulina suddenly became suspicious, spoke in enigmatic tones, seemed to perceive reality differently. She had hardly slept and began to say confused things. I remember the moment when she suddenly accused me of working against her, of conspiring with others against her. It was like a slap in the face. Our once close relationship suddenly felt fragile. Finally, when she could no longer cope with everyday life, I took her to the hospital.

But it was not an easy decision. The first few weeks in hospital were terrible for me. Paulina seemed so different. She was sedated by medication, the doctors called it 'stabilisation', but to me she just seemed dazed. Where was the vibrant, intelligent daughter I knew? I wondered if I had made a mistake. Should I have kept her at home and helped her myself?

The counselling sessions at the family self-help organisation were a lifeline for me. First, I was explained what psychosis was and why medication was important. The counsellor listened patiently, answered my many questions. Later she helped me to see the small steps forward that I had previously overlooked: Paulina's speech became clearer, her anxiety lessened and she began to seek contact with me.





The discussions with my daughter and the doctors were particularly valuable. At first, I felt I had to mediate between her and the medical world - as if I were her translator. But gradually she began to ask questions herself, to bring in her own perspective. It was a long road, but I could feel that she was fighting her way back bit by bit.

I had to learn to let go. That was probably the hardest thing for me. I always wanted to be by her side, to protect her, to take away any uncertainty. But I realised that she needed time and space to grow. Step by step, I managed to reduce my visits to the hospital from almost daily to twice a week. This was a relief for me and gave her the chance to become more independent.

Fast forward: Two years later she is back at home and still has a long way to go, but I can see progress. There are moments when her anxiety comes back - when she seems quiet and introverted, or starts working late into the night again. But I have learned that sometimes it is enough just to be there and trust that she will find her way. Paulina has made a new start. And in a way, so have I.

Main topics covered in this story

Behaviour and disease manifestations of the daughter Paulina:

Psychotic symptoms; Disorganised/Incoherent behaviour; Other psychopathological symptoms; Being stressed by external factors

Experiences and emotions of the mother Ulrike:

Distress; Care dilemma – more or less care and control; Appraisal of others; Positive attitudes of family member

Other main topics:

Services and Professionals; Therapy-related issues; Information deficits





24 Theresa - living together with both a sick son and a sick husband

Theresa is the 63-year-old mother of Martin, who was diagnosed with schizophrenia two years ago at the age of 25. Theresa has a particularly difficult situation since also her husband has been suffering from a psychosis for many years. She describes her complex living situation under these circumstances. (48 words)

“I try to be as supportive as I can”

My husband, to whom I have been married for 35 years, suffers from a schizoaffective psychosis, and it took him a long time to accept this. I am a nurse and at first, I thought I could somehow control everything. For years, I tried to support him by encouraging him to take his medication and follow his therapies. It was a balancing act - I wanted to help him, but at the same time I felt I was constantly overstepping boundaries.

Three years ago, I decided to change the situation and find a new approach. I knew I couldn't go on like this. I went to a family self-help organisation for advice and it helped me to find a different way of dealing with my husband. He now manages his treatments completely independently and it has brought some peace to our relationship with less conflicts.

But just when I thought things were getting easier, our son Martin received the diagnosis of schizophrenia. Before I come to this, I would like to stress that he always had a problematic life.

While he had been a quiet child, always well-behaved and well-adjusted, he had periods of depression in his teenage years. He underwent psychotherapy, which helped him at the time.

Work had always been a big issue for him. He had wanted to feel independent and worked in several companies for many years to earn a living. But these jobs were often temporary. I could always see how much he was affected by his job problems, but he hardly let me get close to him. At the same time, I knew how important it was for him to stand on his own two feet.

He never managed to bring himself to leave his home. There was always tension between him and his father, and I often found myself in the role of a mediator.

When he lost his job two years ago - he had just become 25 - he started to show fears of persecution and became increasingly distrustful of myself and especially my husband, which finally led to him being diagnosed with schizophrenia.





Unfortunately, he strictly refuses medication, which makes it even harder to help him. What is particularly distressing is the thought that my husband and I have set a bad example for him in dealing with his illness. My husband was in denial about his own illness for many years, and I think this had a strong influence on Martin's attitude to psychotropic medication. There has never been an honest conversation with his father about the illness, and I don't know if that will ever be possible.

I try to be as supportive as I can. There are days when he panics and asks me for help. Then I get in the car and drive him around until he calms down. It's exhausting and often frustrating because I know it's not a long-term solution. But in those moments, I have no choice.

At the same time, I think a lot about my own situation. My husband is acutely psychotic again and I realise that my strength is limited. I have even thought about separating, although I never thought it would come to this. When I told my son, I was surprised at how calm he was. In fact, he seems to welcome a separation - perhaps because he feels it might give us all some breathing space.

Main topics covered in this story

Behaviour and disease manifestations of the son Martin:

Psychotic symptoms; Other psychopathological symptoms; Insight into illness/Compliance with therapy; Disease course

Experiences and emotions of the mother Theresa:

Distress; Care dilemma – more or less care and control; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Therapy-related issues





25 Lucia - a mother caring for her son

Lucia is the 63-year-old mother of her 24-year-old son Ali, who was diagnosed with schizophrenia at the age of 19. Lucia describes a slow process of increasing withdrawal since Ali's puberty years with dropping out of school and finally having hallucinations and delusions. Participation in a special early intervention programme was the turning point to a largely satisfying situation today. (60 words)

"It feels good to have a little space of my own again and to be active outside my role as a mother"

We haven't had an easy journey as a family. We had to flee our home country when my son Ali was a toddler. It was a difficult time for all of us. My first husband, Ali's father, was violent and we went through a lot together. I thought at the time that a fresh start in a safe environment would make things better.

Already in his early teens he was showing signs of mental health problems that we couldn't quite put our finger on at first. The real problems started when he was 14 or 15. He became withdrawn, often seemed absent and overwhelmed. He dropped out of school at 17 and it was all downhill from there: no structure to his day, no friends, no prospects. He would often just lie there and seem to be in another world.

After some time, we realised from some of his remarks that he had strange ideas about people persecuting him. When he started to talk to himself and told us that bad people were talking to him, we sought professional help. He was admitted to a psychiatric department and received the diagnosis of paranoid schizophrenia. The doctors rarely involved me and I found it difficult to accept his illness.

He was discharged after a couple of weeks. The doctors had prescribed medication and also suggested that he should receive both psychiatric and psychotherapeutic outpatient treatment. Ali agreed to take medication. But I always felt that things were moving very slowly. I felt left alone for a long time.

Fortunately, after listening to a radio programme I became aware of the existence of a family self-help organisation and went there for receiving help. This was a turning point for Ali and myself. I attended self-help groups, and in one of the sessions I learned from another mother that a psychiatric department in town offered an early intervention programme. I went there and applied for participation and after a short waiting time Ali received a place in the programme.



Through participating in this early intervention programme, Ali has slowly found new perspectives. It has been a long process, but now he goes to his appointments with the social psychiatric service on his own. I wouldn't have thought that possible a year ago. He has even taken part in taster days at various companies and is now planning to start an apprenticeship as a painter. This will give him structure and a goal - something he has lacked for a long time.

A lot has changed for me too. I have started to see things from his point of view and that has improved our relationship. He trusts me more and I've realised that it doesn't help to constantly push him or impose my ideas on him. Instead, I try to support him where he really needs it.

In addition, I have learned from attending counselling sessions at the family self-help organisation that I can't always focus on him. For years, I focused almost exclusively on his needs and completely ignored my own. But I've learnt that it's just as important to look after myself. I am finding time for myself again. I have joined a choir and I am riding my bike again. I am slowly reviving the social contacts that I had neglected over the years. It feels good to have a little space of my own again and to be active outside my role as a mother.

It's not an easy road and there will always be setbacks. But I've learned to see things in a more nuanced way. It's not about making Ali 'healthy'. It's about dealing with the situation and celebrating small victories. I'm proud of my son and myself. We've both been through a lot and we're continuing on this journey together.

Main topics covered in this story

Behaviour and disease manifestations of the son Ali:

Psychotic symptoms; Inactivity/Blunting; Strange behaviour (not aggressive); Insight into illness/Compliance with therapy; Disease course

Experiences and emotions of the mother Lucia:

Care dilemma – more or less care and control; Appraisal of others; Positive attitudes of family member

Other main topics:

Employment, Education, Finances of family member and patient; Services and Professionals; Therapy-related issues; Stigma, Discrimination, Social network, Public realm



26 Klaus - a father caring for his son

Klaus is the 57-year-old father of Noah, who is now 18 years old and was hospitalised for a first episode of schizophrenia only six months ago after a prolonged period of taking cannabis. Klaus lets us participate in the family's confusion and helplessness of living with a son who after discharge from hospital refuses treatment and any form of help, with the outcome currently still open. (66 words)

“Sometimes I think I could just run away because I don't know what to do”

After finishing school, when my son Noah was about 15 years old, he got into a bad crowd of friends and started using marijuana. Because he needed money, he took on a job in a supermarket, where he was dismissed after a couple of months, then tried again in another supermarket with the same result. He rented a flat with a friend, but ran out of money because he wasn't working and hadn't registered with the Public Employment Service and he moved back to us.

His drug use led to many conflicts with us parents and the situation kept escalating. Since we didn't know how to react, we parents consulted a psychologist, recommended by a good friend of ours. After having explained our situation, the psychologist told us to stay calm and everything would go away by itself.

But the problems did not go away, on the contrary. Six months ago, Noah began talking about creatures he had seen and saying that he had received supernatural instructions to perform special rituals. We couldn't make sense of this, especially also because his speech was incoherent. We were very scared by these statements. First, we thought this might be an overdose of a drug he had taken, but then we contacted our GP, who recommended that we see a psychiatrist. He strongly recommended an admission to a psychiatric ward. Surprisingly, after some discussion, Noah agreed to hospitalisation.

Noah was discharged after six weeks of hospital treatment with the diagnosis of schizophrenia and the recommendation to continue with medication. When he came home, it was a difficult time for all of us again, but at least we had an explanation for his behaviour. Unfortunately, he neither took his medication regularly nor attended the psychiatric appointments we had arranged for him. He said that he had now reached the age of 18, where he could make his own decisions.

We felt helpless again and were back to square one. He withdrew more and more, refused to be helped and took no responsibility for himself. There are many difficult moments when we





feel completely helpless. For example, a couple of days ago at lunch he suddenly started talking about parallel universes, then about sounds and their meaning - it was completely incoherent. He explained why he didn't want to work and asked us to leave him alone. It was a mixture of confused thoughts and incomprehensible statements.

Two months ago, I noticed that he had injured his arm. There were scars, which have now healed. It scared me and I still don't know what it means. It's hard for me to stay calm when he says confused things again, or when I see him hurting himself. Sometimes I think I could just run away because I don't know what to do.

It feels like he's living more and more in his own world. I'm trying to stay calm, but it's getting hard. We can't really help him without the right treatment and he refuses any kind of support. It really gets to us because there are days when we just don't know what to do. Even more so, since in the last few months we were getting more desperate and had the feeling that hope diminishes.

My wife and myself have now contacted a family self-help organisation and met several other parents who have similar stories. It is a kind of relief to see that we are not alone with our problem. Since everything is very new, we are still in an uncertain situation, but we now got a glimmer of hope, that we will eventually be able to take the right steps to find a way to get help.

Main topics covered in this story

Behaviour and disease manifestations of the son Noah:

Psychotic symptoms; Disorganised/Incoherent behaviour; Inactivity/Blunting; Self-harm; Insight into illness/Compliance with therapy

Experiences and emotions of the father Klaus:

Distress; Positive attitudes of family member; Patient moves out of/back to the family home

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Physical health of family member/patient; Services and Professionals; Therapy-related issues; Information deficits





27 Marlene - a mother caring for her daughter

Marlene is the 60-year-old mother of Louise, who is 28 years old and was diagnosed with schizophrenia 6 years ago. Marlene describes at length how she and her family increasingly understood the behaviour and disabilities of Marlene and managed to provide an environment appropriate to her special life situation. (49 words)

"We have learned that her withdrawal is often a way to recover from the stresses of life and find some peace"

At the beginning, we didn't know what to expect. Our daughter Lousie had no insight into her illness for a long time, so we as parents were the ones who had to make decisions and take actions – often without knowing exactly what was right. Over time, we sought professional help, and it was important to recognise our own limits. We had to learn to delegate tasks and share responsibility.

A turning point was when our daughter herself was willing to accept help. We built up a network of professional support that continues to help us today. Our daughter now accepts this help, which is a great relief. However, it was not always easy to step out of the carer role. Often, our ideas of a 'good life' were at odds with what our daughter wanted or was willing to accept. Earlier we had tried to keep our hopes of recovery alive by being active. However, it happened that we were more focused on our own concerns than on her current needs.

My husband now describes himself as our daughter's companion. 'I see myself as someone who helps her to develop and works on the relationship,' he says. 'It requires a lot of flexibility and is often like a to and fro - back and forth. It's not always just forward. But we all learn from each other.' Especially at the beginning, it was difficult for him to deal with our daughter's speechlessness and emotional distance. But with growing experience and understanding, we are both learning to deal with it better.

For us, it is not so much a role as an attitude. As parents, we remain connected to our daughter, regardless of her behaviour. We offer her our presence and never lose sight of the fact that behind the illness, the healthy nature of our beloved daughter always shines through. This conviction – that sensitivity and kindness are always present and visible – helps us to stay connected to her and keep going even in difficult times. This idea of fundamental health underpins our relationship.

Our daughter also receives support from other family members. She occasionally spends time with her brothers and sisters, grandparents and aunts. She can visit or call them and feels accepted by them. Shared activities such as cooking or going on holiday are particularly helpful





for her and for us. However, this was not always the case. At first, her brothers and sisters kept their distance and avoided contact. Now they have found ways to spend time with their sister.

Getting our daughter involved in a support network was a big step forward. She now lives in a shared flat, has a work structure and a personal professional carer. This has relieved us of many tasks. It was a learning process to trust her to take responsibility for herself. Our confidence in her ability to develop has grown over the years.

It was particularly important for us to find our way around the care landscape. We have learned to use networks such as a family self-help organisation and a specific setting for exchanging thoughts with other relatives, people affected by a mental illness and experts (called “Triologue”). This helped us to gain new perspectives and better understand support options such as medication and other treatments.

My husband says: ‘Sometimes when I see young people in professional training, in relationships or hanging out with friends, I feel sad that our daughter is limited in her options.’ But over time, we have learned that her withdrawal is not always a sign of relapse or a psychotic episode, but often a way to recover from the stresses of life and find some peace. We appreciate that she has found her way, even if it is different from what we might have imagined.

We now also understand that participating in everyday things from a distance, such as sitting in a café or on a bench, is her way of being among people without feeling overwhelmed. It is her life, and I have learned to respect it as it is right for her.

Looking back, we realise that seeking professional support has been particularly helpful for us. It has helped us to recognise our own limitations and to let go of the idea that we have to do everything alone. Today, we share responsibility with a network of people, and our daughter has people by her side whom she trusts. This process has strengthened us as a family and enabled us to better deal with the challenges of her life and our role as relatives.

Main topics covered in this story

Behaviour and disease manifestations of the daughter Louise:

Inactivity/Blunting; Insight into illness/Compliance with therapy

Experiences and emotions of the mother Marlene:

Distress; Care dilemma – more or less care and control; Appraisal of others; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Services and Professionals



28 Celine - a daughter caring for her mother

Celine is the 26-year-old daughter of Magdalena, who is 51 and was diagnosed with schizophrenia when Celine was born. Her father also has mental health problems. Magdalena vividly describes how she always had to care for her parents, experiencing a reversal of the parent-child role, but she also learned that taking care of herself was essential for assisting her parents. (60 words)

“The parent-child role between me and my parents has always been reversed“

I grew up with my mother, my grandmother and my great-grandmother - these three women have had the greatest influence on my life. My mother Magdalena had paranoid schizophrenia and was in and out of hospital. My grandmother was helpless. My great-grandmother was my biggest help until she died when I was 13 and I lost my main support during a turbulent time.

My father was also part of this difficult family situation. He was deluded and believed in conspiracy theories, which intensified during the coronavirus pandemic. However, he has never received a formal psychiatric diagnosis. The contact with him was very stressful and I had to stop seeing him for a while because our communication just didn't work.

The parent-child role between me and my parents has always been reversed - also known as parentification. My parents often couldn't or didn't want to take on their parental roles, so I ended up taking on this responsibility because I had no other choice. I took it on because I felt I wanted to give direction to what was happening. It meant looking after my sick parents, organising the household and never being able to rely on them being there when I needed them.

Over time, I began to think about the changeability of family roles. I am now in therapy and try to create places of retreat where I can reclaim my role as a daughter. Something has changed, especially with my father. I had stopped communication with him for a while, but recently I reversed this to see how he would react. We now consciously talk about things that connect us, such as nature conservation and woodworking - subjects in which he, as a carpenter, has a lot of experience. But if the conversation drifts into problematic areas, I stop it to maintain my boundaries – however this has not happened for a long time now, and that feels like a small step forward.



My relationship with my father is still difficult but loving. He tries to see me as a daughter and can be fatherly when I am not well. I recently wrote to him about my sadness about many societal developments. He said that I am an especially sensitive person, which he is as well. He concluded that he needed to take special care of me and be mindful with me. That was nice to hear, and we were able to experience something new together, and something was healing. Nevertheless, our relationship remains reduced, but such moments feel like a loving father-daughter relationship.

It had not been like that before. My father lived in the countryside, and we only saw each other during the summer months or at Christmas, when he sold wooden toys at markets. When I was 12, he told me that he now saw me as an adult. At the time I didn't find that uncomfortable, but now I find it problematic. He was giving me responsibilities and pushing me into things that children should be protected from. He saw me as the 'sensible' daughter and took little responsibility himself, which was ultimately part of his illness.

I now have a great deal of understanding for the stresses he experienced in his own childhood. As the eldest son, he had to take over the family farm and his father was a very strict man. But my father is a very sensitive person, and I think he didn't want to behave the way his father did. Nevertheless, he didn't know what it meant to be a father and to protect me from making bad choices. He saw me as an independent child and didn't realise how overburdened I often was.

This ability to put myself in someone else's shoes helps me to understand many of his reactions. But it also makes it difficult to draw the line when I have to give him the responsibility for his behaviour. I try to remind myself that I am not responsible for his illness, but I don't always succeed. However, I have now learned to manage my sensitivity and have built up a support network of understanding people with whom I can be honest.

By comparison, little has changed with my mother. She is much more limited than my father because of her illness, and I still have many responsibilities towards her. It's hard for me to draw the line, but I try to stay in my daughter's role and look for moments when she can actually be motherly. Once, when I was with her and crying, she asked me if I needed a handkerchief. In that moment she was able to come out of her 'captivity' and offer me something. Moments like that are rare, but they are important. She is often slow to respond to my needs. If I tell her I have a headache, she takes minutes to ask if I need an aspirin. She hears voices when she is psychotic and then becomes completely withdrawn. It is difficult to always know the right time to visit her without using too much of my own resources.

I have learnt to consciously decide when to take on the role of helper. My mother has a social worker, and I often delegate things to the social worker when I feel overwhelmed. But I don't





want to abandon my mother completely. I help her organise her care and always make sure that I can help her emotionally and practically.

When I was young, I had surrogate parents like uncles and aunts to support me. It was important that they were there, even though their help was often tied to conditions. I always had to show my gratitude very clearly for these relationships to last. There was no room for 'youthful recklessness' if I didn't want to lose their closeness.

And here's something else I can highly recommend for finding a bit of stability: cats.

Main topics covered in this story

Behaviour and disease manifestations of the mother Magdalena:

Psychotic symptoms; Inactivity/Blunting; Disease course

Experiences and emotions of the daughter Celine:

Other challenges; Appraisal of others; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Services and Professionals



29 Natascha - a mother caring for her son

Natascha is the 54-year-old mother of her 24-year-old son Robert, who was diagnosed with paranoid schizophrenia 5 years ago. Robert is on medication, has a girlfriend and is able to manage his daily life to some extent. But he has not found a permanent employment, which worries his mother, who repeatedly describes her dilemma between wanting to push Robert to take on a job and her fear of too much intrusion into his autonomy. (74 words)

“What will happen when he is no longer able to look after himself?”

My son Robert has been on medication ever since he had his first episode of paranoid schizophrenia five years ago, and it seems that medication is helping a lot. It is good to see that today, after many difficult years, he is able to manage his daily life to some extent. He has a girlfriend who is very important to him and he is in regular contact with us, his family.

Despite this progress, there are still many challenges. Robert still has difficulty finding permanent employment. Last autumn he had a job for three months but left because he felt overwhelmed - perhaps also because of problems with the employer. Since then, he has been doing odd jobs, such as filming and editing videos. These jobs help him earn a little money, but it's not enough to provide long-term security.

I have often talked to him about the importance of taking the next step and finding a stable job. But whenever I bring up the subject, he retreats. It's not that he doesn't understand - he knows he needs to take action, but somehow, he keeps falling back without changing anything. I find it hard to understand what the problem is. I know his illness closes a lot of doors, but at the same time he seems to have the strength to do things - just not the right things.

I worry about his future. At the moment, we get double family allowance for him, and my husband and I pay a lot of his living expenses. But I wonder how long that will last. What will happen when he is no longer able to look after himself? I want to give him the time and space he needs, but at the same time I'm afraid that he'll withdraw more and more and never dare to take the step towards independence.

It's not easy to find the right way to help him. There are moments when he shows a desire to do something, but the fears associated with his illness often prevent him from acting on that



desire. I want to give him the space he needs, but also make sure he doesn't get stuck in a situation where nothing changes.

One example that has stuck with me is that some time ago he had a job opportunity that he turned down. I felt that he wasn't really grasping the opportunity, but was paralysed by the thought of what might happen to him, if I pressurized him to try harder and take responsibility - in moments like this I imagine that his fears and insecurities could take over and lead to a breakdown.

I hope that one day he will find the courage to take the next step. I want to support him without pushing him, but at the same time show him that it is in his hands to bring about change. Ultimately, I want him to feel that he can take care of himself, although I will always be there if he needs me.

Main topics covered in this story

Behaviour and disease manifestations of the son Robert:

Being stressed by external factors

Experiences and emotions of the mother Natascha:

Distress; Care dilemma – more or less care and control; Appraisal of others; Positive attitudes of family member

Other main topics:

Employment, Education, Finances of family member and patient; Therapy-related issues



30 Olivia - a sister caring for her brother

Olivia is the 58-year-old sister of her 66-year-old brother Stanislaus who was diagnosed with schizophrenia 43 years ago, when he was 23. Olivia describes at length her distressing experiences as a teenager of her brother's disease and the year-long inability of her parents to deal with it, and how she finally came to terms with her brother's disease after joining a self-help group of affected siblings. (66 words)

"It is important to seek help - breaking the silence is the first and most difficult step"

When my brother's illness broke into our lives 43 years ago, the world as I knew it collapsed. Everything changed. My mother clung to the hope that one day everything would be back to the way it was. She didn't want to face reality, which I can understand - it would have hurt her too much. But this 'just a little longer and everything will be fine' kept the family in a paralysing state for many years.

I was very young then, just 15 (and 8 years younger than my brother) and could hardly understand the situation. At first, my brother spent almost a year just lying in bed. Then came the first crisis when he thought we were poisoning him. There were many such moments that were difficult to bear, and some are still associated with fear today. All of us lived in a two-room flat, which made the situation even more unbearable. Each of us withdrew into our own inner world. My brother's illness had changed us all and reshaped our daily lives.

Therapy options were few four decades ago and mainly limited to medication. We as a family were hardly involved by the treating physicians. There was no discussion about how we could help as relatives, no information about the disease and its dynamics. Instead, we were presented with a fait accompli regarding my brother's medication. When he was in hospital, it was as if the family were invisible. As soon as he was discharged, we were fully responsible again. It felt like we had no voice and no support. This dehumanisation and ignorance of the role of the family was humiliating for all of us.

My brother and I were never very close. I was much younger and always wished to be closer to him. He was a role model for me before he became ill. With his illness, I lost the brother I had known and admired. I had hoped that in time, when we were older, we would develop a closer relationship. But that never happened. Instead, in bad times, we were often bound only by his rules and demands. Sometimes I had to take a lot of insults from him. It was painful to see how



he behaved towards my mother and me. But I knew it wasn't really him - it was the illness. Still, it was hard to endure this dynamic.

In the family I became invisible. My parents never really got to know me. Outwardly, I seemed like a child from a good home - quiet, well-behaved, unremarkable. But inside I was in turmoil. I didn't want to 'add to the problems', so I held back and tried to be the 'good girl'. Inside I felt sadness, anger and loneliness. At the same time, I felt guilty for having these feelings in the first place. It was a constant struggle.

It was especially hard because I was very sensitive as a child and I could clearly feel the unspoken tensions in our family. I felt responsible, particularly for my mother. I always hoped to cure my brother first and then think of myself. I denied myself my adolescence because I was too busy taking responsibility.

Over time, I made peace with my family, my past and myself. Today I tell myself a different story about my life, knowing well what it was like. I want to live in the here and now, without the past or the future interfering with the present. I have learned to give myself what I didn't get from my family. It's never too late for a good childhood, as they say, and I have decided to live my life in such a way that I am well today.

It was only when I came across a supportive community for people who have a seriously ill or deceased sibling that I realised I was not alone. For the first time, I was able to talk about my experiences and realise that siblings have a story too. It was here that I learnt that happy moments were not a betrayal of my family, that I was allowed to be free. Talking about our experiences together showed me that we are all fighting similar battles and that it is important to support each other.

Today I am at an age where the past and the future are in balance, but the memories of the past remain and the wounds are slow to heal. It is important to seek help. Breaking the silence is the first and most difficult step. But it is worth it. Among like-minded people, you will find that you are not alone, that you are not a traitor, but a human being with your own story. Have compassion for your parents, your siblings and most of all for yourself. Live your life because you have the right to be happy. Use your experiences to become stronger and more compassionate. Everyone has a story, and we can make something beautiful out of ours - something to share with others.

Main topics covered in this story





Stories of Care

Navigating mental illness together

Behaviour and disease manifestations of the brother Stanislaus:

Psychotic Symptoms; Inactivity/Blunting; Aggressive behaviour

Experiences and emotions of the sister Olivia:

Distress; Appraisal of others; Positive attitudes of family member

Other main topics:

Services and Professionals; Therapy-related issues



31 Jana - a sister caring for her sister

Jana is the 40-year-old elder sister of the 36-year-old Sabine who was diagnosed with schizophrenia 15 years ago at the age of 21. Jana describes a story of success – how, with the help of her family and friends, and also with medication and psychotherapy, her sister learned to live with her disease and became successful in life, even getting a degree at university and living now with a partner. (69 words)

“Over time we realised that patience is the key to success”

My sister Sabine has been suffering from schizophrenia for more than 15 years. Despite this serious illness, she has managed to build a happy and fulfilling life for herself - and I couldn't be more proud of her.

The onset of Sabine's illness came as a great shock to all of us. She was under a lot of stress at the time - she had difficult exams at university and many worries in her personal life. In late summer we noticed that something was changing in her. I remember that our brother was the first to say: 'Something has changed in you.' Later she told us that she heard voices that frightened her. Finally, she asked us to take her to hospital. The doctors there diagnosed a “stress syndrome with sensory symptoms” and she stayed in the hospital for two weeks.

When she came home, she seemed better at first. But at home she slipped deeper and deeper into a situation of despair. She had visual hallucinations, strange bodily sensations, taste hallucinations and ideas of being persecuted. Her thoughts were full of negative emotions, and she often seemed depressed and confused. It was a very difficult time for all of us, but especially for Sabine. She agreed to be taken to hospital again and there they diagnosed her with schizophrenia.

At first, she didn't want to accept the diagnosis. She couldn't believe it and tried to hide the disease. She didn't talk about it, and it was difficult to find a way to reach her. She just didn't want to admit what was happening to her. But as time went on, she could no longer deny that she was ill.

Eventually she began to come to terms with it. The fact that there is still a certain taboo about talking about mental illness made the process even more difficult. But she eventually could live with the concept that a mental illness is just as much an illness as diabetes.



In the beginning, Sabine had a lot of trouble with the medication. The thought of being dependent on medication for the rest of her life was almost unbearable. She often told me that she would reduce the dose when she felt better. Sometimes she would stop taking it altogether because she thought she no longer needed it. There were times when she would only take half or a quarter of a tablet, hoping that she would be better off without the medication. It was too much for her to stick to the prescribed dose. But now she has learned that medication is important for protecting and preserving her life. However, even with medication, there are still difficult periods when she does not feel well. But she has learnt to deal with them and knows that they will pass.

In addition to medication, psychotherapy has played an important role in her treatment. Sabine was lucky enough to get a place on a health insurance scheme and she took this therapy very seriously. She learnt a lot about herself and gained a better access to her own feelings and thoughts. We always supported her. Her friends, her partner - they all helped her through this difficult time.

Despite her illness, she managed to complete her veterinary degree. She had always dreamed of becoming a vet since she was a child. Either that or a 'people doctor', as she put it as a child. Her unwavering will, tenacity and a little bit of luck, along with her belief that she could do it, helped her achieve her goal. Her belief in what she could achieve was crucial. She kept picking herself up, even when it was very difficult.

Of course, it was also very difficult for us as relatives. It is incredibly painful to see a family member in such a difficult situation and we often felt helpless. But over time we realised that patience is the key to success. The person with the disease has to find his or her own way. Pressurizing and lecturing are usually the wrong approach, even though it is very difficult as a relative to just watch without being able to intervene. We had to learn not to be too critical, but also not to be too protective.

Her journey was not easy, but she never gave up. She learnt to live with her illness and today she gives other people the strength to do the same. I admire her and her strength.

Main topics covered in this story

Behaviour and disease manifestations of the sister Sabine:

Psychotic symptoms; Disorganised/Incoherent behaviour; Other psychopathological symptoms; Insight into illness/Compliance with therapy; Being stressed by external factors

Experiences and emotions of the sister Jana:





Stories of Care

Navigating mental illness together

Distress; Care dilemma – more or less care and control; Appraisal of others; Positive attitudes of family member

Other main topics:

Employment, Education, Finances of family member and patient; Services and Professionals; Therapy-related issues; Stigma, Discrimination, Social network, Public realm



32 Helene - a mother caring for her son

Helene is the 58-year-old mother and the main carer of her son Nico. Nico is 29 years old and was diagnosed with schizophrenia when he was 21. Helene focuses on her experiences with initiating an involuntary hospital admission of her son, her emotions and her assessment of this event in hindsight. (51 words)

“A young police officer told me I shouldn’t worry - they would take good care of him”

The decision to call the police to have a loved one admitted to a psychiatric hospital is certainly one of the most difficult decisions a family member has to make. I never thought I would find myself in this situation and it was one of the worst things I could ever do to my son Nico. But at some point, the situation became so serious that I felt I had no choice.

Nico, with whom I have a good relationship, lived alone at the time. He was suffering a lot from the negative symptoms of his illness - extreme lack of energy and motivation and a very depressed mood. I visited him regularly, tried to bring some order to the chaos in his home, made sure he had enough to eat and tried to motivate and encourage him.

But one day the switch in his head suddenly flipped. During one of my visits, he blamed me for his illness and said I didn't understand or know anything. He didn't want any contact with a woman like me. I was kicked out of his house and for months after that I had no contact with him. Two other members of the family also tried in vain to contact him. It was a painful time for all of us.

I drove past his house regularly, always looking for signs of life: Was the window open or shut? Were the blinds up or down? Was the light on or off? These little clues at least gave me some peace of mind. But the longer it went on, the more I worried. I was afraid he might hurt himself, and when the risk factors were listed when I attended an online lecture on suicide prevention, I could tick off nine out of ten items as applicable to my son. This realisation sent me into a panic. That was the moment I knew I had to do something.

I didn't immediately call the police, but contacted the crisis intervention service. I spoke to a doctor there and we planned everything in great detail. The aim was to get my son out of his situation without having him compulsorily committed to hospital. But as the situation became



more serious and he refused to go to hospital voluntarily, I felt that I had no choice but to call the ambulance and the police.

Looking back, I can say that it was the right thing to do, although in the first days after this intervention I was plagued by feelings of guilt and shame. I could hardly bear to look my son in the eye, thinking that I had betrayed him. Many relatives hear from their ill family member the phrase 'I'll never forgive you for this' after a compulsory hospital admission. But thank God I never heard that from my son. I apologised to him, explained my motives and tried to tell him how much of a burden it all had been on me.

I knew it was the right thing to do. He understood and not only forgave me, but told me he was convinced I had no choice at the time. Today, after seven years and many conversations, we can even talk about it with a certain sense of humour, which really helps me. It was a difficult process, but in the end, it brought us closer together.

As for the police and the medical officer, I can only report positive experiences. The medical officer spoke mainly to the psychiatrist on the crisis team, which was confusing for my son. But there were also very reassuring moments. I particularly remember a young police officer who noticed how upset I was. He said to me: 'Don't worry, we'll take good care of him.' Those words gave me an incredible amount of comfort and reassurance.

My son has now accepted that he is ill and is very thoughtful about how he deals with his illness. He takes his medication regularly and only goes to the doctor once a year. I am glad that he has taken control of his treatment, and I trust that he will seek the help he needs if he needs it.

My advice to relatives in a similar situation would be to remain calm during the intervention and to explain the background to the police and doctors as well as possible. It is important not to have any false expectations about calling the police for help, as a compulsory admission can only take place under very strict legal conditions in our country.

In the event of a compulsory admission to a psychiatric ward, relatives should ask the patient's lawyer (who exists in all psychiatric inpatient units) about the procedure and their rights. But the relationship with the affected person is also crucial: you should never lose sight of the person's personality, but show that you have acted out of concern and love. It helps to talk about what both sides have experienced later, but you should wait for the right moment to have these conversations. A little patience is needed - 'good things take time'.





Main topics covered in this story

Behaviour and disease manifestations of the son Nico:

Disorganised/Incoherent behaviour; Inactivity/Blunting; Other psychopathological symptoms; Blaming; Insight into illness/Compliance with therapy

Experiences and emotions of the mother Helene:

Distress; Other challenges; Appraisal of others

Other main topics:

Relationships within the family of the patient; Services and Professionals; Therapy-related issues; Legal issues and police involvement



33 Irene - a mother caring for her daughter

Irene is the 74-year-old mother of Sophie, who is now 48 years old and was diagnosed with schizophrenia, when she was 23. Irene relates that Sophie was originally a bright child, but then lost energy and was not successful in her medical studies. Irene was struck by lightning, when Sophie's strange behaviour in public suddenly led to her being hospitalised. (60 words)

“As a layperson you are helpless. You see the changes in behaviour, you look for explanations, but a mental disorder?”

You always want to do the right thing, especially when it comes to your children. When I was pregnant with Sophie, I read a parenting guide that recommended not to pick up a crying baby immediately - every four hours at most - to avoid spoiling the baby and to give yourself a break. I still regret following that advice, even though I wanted the best for Sophie. So, I did what the book said. I let her cry. It was horrible to see her like that, sometimes she would literally scream until her face turned blue. One day my gynaecologist said, 'Follow your heart! If she cries, pick her up!' So, I did, but I've always felt that that early period permanently damaged our relationship.

My husband worked a lot, and I also had to earn money because my father had multiple sclerosis and we needed every penny. It was never possible for me to go to university, although I would have liked to. Instead, I worked while my mother-in-law looked after Sophie. She was a lovely woman and took good care of Sophie. She looked after her so well that by the time Sophie was six, my daughter thought she had been born to her grandmother. I remember explaining to her that I was pregnant with her brother. She looked at me in amazement and said: 'I came out of you too?' I said: 'Yes, of course, I'm your mother!' And she replied: 'I thought I came out of my grandmother!'

Sophie was a bright child. In elementary school she was top of her class, and in high school she was among the best. She had a talent for languages, an interest in science and seemed to have a bright future ahead of her.

But in third or fourth grade, she began to change. She lost the joy of learning, her performance deteriorated and she became withdrawn. I put it down to puberty and the fact that we - my husband and I - were so busy all the time. When she was 13, she sat motionless in her school



desk, her teacher told me. At home she became increasingly unruly and began to turn against me. Everything I said was wrong in her opinion.

After leaving school, Sophie started medical school. She wanted to specialise in brain research, a field that fascinated her. But even though she studied for several years, she barely took any exams. Her first big exam was in chemistry and she failed because she hadn't studied. My husband suggested that she change to a different faculty, but that was out of the question.

Eventually she passed the chemistry exam, but she made little progress. We supported her as much as we could - she had her own room and we provided everything she needed. But she was always dissatisfied. She often accused me of loving her brother more than her. Maybe she was right. Things were so much easier with my son.

I never thought she might be ill. As a layman you are helpless. You see the changes in behaviour, you look for explanations, but a mental disorder? That was unthinkable for me. But then, when Sophie was 23, I got a call from the library where she worked because she had locked herself up in the library - naked. I didn't know what to do. In desperation, I called a doctor friend who advised me to call the police and have Sophie admitted to hospital.

She was taken to the nearest hospital and then transferred to a psychiatric department. There she was finally diagnosed with paranoid schizophrenia. I remember the doctor telling me the diagnosis. He was cold and distant, handed me a piece of paper with the address of a family self-help organisation and said that they would explain everything to me there. When I left, I was standing outside the hospital. It was winter and there was snow between the pavilions of the hospital. I looked up at the sky and never felt more hopeless than at that moment.

Sophie came home. She had been given medication - but the side effects were terrible. She couldn't sit still, paced restlessly and screamed that it wasn't fair. I felt guilty, as if I had failed. As a mother, you feel responsible for everything. I finally contacted the family association and found a lot of support. They explained to me that I wasn't alone and that many other parents were going through similar situations. This helped me to start questioning my feelings of guilt and understand that I couldn't control everything.

Today, two decades later, Sophie has accepted her illness. She is now staying in a supported living facility, has a day structure and actually is learning French in an adult education centre. I see her once a week, when we undertake some activities together, like going for a walk or to the cinema.





Main topics covered in this story

Behaviour and disease manifestations of the daughter Sophie:

Strange behaviour (not aggressive); Blaming; Insight into illness/Compliance with therapy;

Disease course

Experiences and emotions of the mother Irene:

Distress; Appraisal of others; Positive attitudes of family member

Other main topics:

*Relationships within the family of the patient; Physical health of family member/patient;
Services and Professionals; Therapy-related issues*





34 Charlotte - a mother caring for her daughter

Charlotte is the 81-year-old mother of Judith, who was diagnosed with schizophrenia 35 years ago at the age of 21. Her mother describes the turbulent life with her daughter, who had no insight into her illness and who never recovered. Judith died of a medication overdose five years ago. (49 words)

“There was a hail of accusations from all sides and I felt terrible”

When I look back on the years with my daughter Judith, I still have this nagging feeling that I could have done more. Yes, sometimes I blame myself, although I know I tried very hard. Thirty years ago, Judith was at home and taking her medication only sporadically. As soon as she felt better, she would stop taking it. She had no insight into her illness – she had been diagnosed with paranoid schizophrenia - and that had made everything so difficult.

We had the police in the house at least once a year. She was desperate to live alone, so we found her a small flat on the third floor of the house where we lived. She often locked herself in her room and wouldn't answer when we knocked. We never knew how she was.

One day the police and the fire brigade had to break down the door to her flat. I will never forget the scene: my daughter was huddled up in her bed, completely apathetic. She was no longer able to use the toilet. She was involuntarily committed and taken to hospital. There I was asked why I hadn't taken better care of her. She had lice. There was a hail of accusations from all sides and I felt terrible.

The neighbours saw everything too. You can't hide anything in a house with several tenants. Judith would often start screaming in the middle of the night. She would lie in bed with the window open and her screams would echo across the courtyard.

She kept claiming that we were going into her flat when she wasn't there and taking things away. She often put her childhood doll's house dishes on the table. I once asked her why she was doing this and she replied, 'Don't think I'm always alone. I'm never alone because they're all with me'. She was talking to supernatural beings, and she was convinced that they existed.

Looking back, I remember something, which was perhaps the first sign of her disease. In primary school, she had an imaginary friend called Oline with whom she often talked. I didn't think anything of it at the time. Children have vivid imaginations. But later, when her illness had fully developed, it all made sense.





Judith was admitted to a psychiatric hospital at least 20 times over the years. It was a constant up and down. And at some point, I reached my limit. When she came home from hospital and my husband was at the end of his tether, I confronted her. I said: 'Either we find a solution so that we can live together in the house normally. It's not working anymore. We have other problems. Your brother has to study now and we need peace in our family. Or you can find your own place somewhere else.' I knew it was hard, but it had to be said.

We found a supported flat for Judith. She moved there, but she refused any form of authority. She didn't take her medication and did what she wanted. She was in her late 40s at the time. I used to get phone calls when something had happened again. She later moved to a shared flat in another area, but there were problems there too. Twice a year everything fell apart.

Once she was even arrested and sentenced to prison for theft. I remember going to the police station and to court. It broke my heart.

Five years ago, Judith died of an overdose in her apartment. Her death left a void that I still feel today. My husband, who was very busy with his work all his life, shared my grief. He died of the corona virus three years ago. And me? I had never stopped thinking about her. I had always hoped that there might be another way for her. The pain we have all endured remains. It has been a difficult journey. Judith was a part of me and I hope she is at peace now.

Main topics covered in this story

Behaviour and disease manifestations of the daughter Judith:

Psychotic symptoms; Disorganised/Incoherent behaviour; Inactivity/Blunting; Strange behaviour (not aggressive); Self-harm; Insight into illness/Compliance with therapy

Experiences and emotions of the mother Charlotte:

Distress

Other main topics:

Relationships within the family of the patient; Physical health of family member/patient; Services and Professionals; Stigma, Discrimination, Social network, Public realm; Legal issues and police involvement





35 Monika - a mother caring for her son

Monika is the 52-year-old mother of Andi, who is 21 and was diagnosed with schizophrenia one year ago. Monika describes how she struggled to understand what was going on when Andi's behaviour changed, and how she is still trying to cope with Andi's ambivalence regarding his treatment, which he sometimes accepts and sometimes rejects. (54 words)

“At first I thought it was just a crisis – but the longer I talked to him, the more I realised that he was living in a world of his own”

About a year ago, my son Andi came back from Australia. He had completed a bachelor's degree in business there, and everything seemed perfect. But soon after he got back to Austria, he started to change. At first, I didn't think anything of it, maybe he was just exhausted from the long journey or overwhelmed by his return. But it got worse and worse. He kept talking about being a 'world healer'. I couldn't believe it. I thought it was just a 'phase', maybe a bit of a crisis after coming back from abroad. But the longer I talked to him, the more I realised that he was living in a world of his own.

He was becoming more and more withdrawn, didn't want to do anything with friends or family. And then there was the cannabis use. I knew he smoked weed occasionally, but now he was doing it more and more often, as if it helped him to come to terms with his thoughts. But I also knew it was not the answer.

I work in social services myself and I thought I could use my skills to help him. I talked to him a lot, tried to understand what was going on in his mind, tried esoteric methods to calm him down. But nothing helped. He became more and more trapped in his delusions. I realised that I was getting nowhere, that I might have missed something. At some point, I had to admit that my son was ill.

It was a difficult moment when I took the courage to talk to a psychiatrist. She confirmed what I had suspected in my heart: my son was suffering from schizophrenia. I was devastated, but also somehow relieved. It had a name, I had an explanation for what was happening. But the diagnosis was only the beginning.

Andi and I were very suspicious of psychiatric help. He had a deep aversion to medication, and I had no knowledge about psychotropic drugs. This made us both sceptical. But the psychiatrist advised us to get him professional help - and above all that he should take medication. I could hardly believe it, but I knew I had to do something. Something had to change. I decided to get advice from a family self-help association I had heard of. Since my husband and I live on the





outskirts of the city, and I was very busy at work, I decided to use telephone counselling to get at least some initial support.

The biggest challenge was convincing Andi to go to the doctor with me. It was a constant battle - I kept explaining to him that he needed help and that medication could help him gain more control over his life. I also told him that I wouldn't leave him alone and that we would get through this difficult time together. It was a tough road, but eventually I was able to motivate him to make an appointment with a psychiatrist.

However, Andi was still not ready to take medication. He experimented with the pills, taking them and not taking them. And cannabis which he continued to use made his condition worse. I saw it, I couldn't ignore it. It was a vicious circle that he just couldn't seem to find a way out of. But the conversations with the doctor began to awaken an awareness in him. I could see that he was beginning to understand that he was ill.

It was a long process, but eventually he asked me for help, and we went together to the hospital. He was admitted for three weeks. It was a small success, but not a breakthrough. After the hospital stay, he did not want to continue with outpatient care.

It was difficult to cope with all the changes in his life. He continued to live with us and it was not an easy burden to bear. My husband could no longer imagine living with him in the long term, and I realised that our relationship was increasingly suffering because of Andi's problems. It also affected my daughter, because I had so little time for her that year. Everything revolved around her brother and his problems.

He finally started doing small jobs, trying his hand at delivery services, but it was clear that he was not ready to return to the world of work. He kept failing, which discouraged both him and me. But one small step forward was that he finally admitted he needed support. I continued to fight for him to get family allowance, but it was rejected in the first instance.

A small ray of hope was that we finally got him approved for assisted housing. But there he was very unruly. He was reluctant to accept support and medication remained an issue that we struggled with. I knew it was going to be a long road, but I hadn't given up hope. Andi and I are still on that journey and it's been quite a rocky road. Sometimes I wonder if I've done enough. But I know I've done my best. And I'll continue to be there for him. Because I also know that he needs me. And I'll continue to help him in any way I can.

Main topics covered in this story





Stories of Care

Navigating mental illness together

Behaviour and disease manifestations of the son Andi:

Psychotic symptoms; Inactivity/Blunting

Experiences and emotions of the mother Monika:

Distress; Appraisal of others; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Physical health of family member/patient; Services and Professionals; Therapy-related issues; Legal issues and police involvement





36 Veronika - a mother caring for her son

Veronika is the 45-year-old mother of her 22-year-old son Emil, who was diagnosed with schizophrenia 3 years ago. Veronika describes how she can't come to grips with Emil's increasing withdrawal, confusion and inability to organise his life, and how she is increasingly exhausted, while she also reports about her doubts about the diagnosis, which is partly due to her experience of being left largely uninformed by professionals. (67 words)

"People who don't know us are quick to judge and label us as negligent parents"

When my son Emil was a teenager, he got into the wrong crowd and started experimenting with drugs. At first, I thought it was just a phase - one of those teenage rebellions that would pass. But as the years went by, instead of finding his way, he became more and more lost.

Today, as a family, we are faced with a situation we can barely comprehend. A diagnosis of schizophrenia has been made, but we are not sure if it is true. Life at home is becoming increasingly difficult and we don't know how to support him without losing ourselves. It's hard to know what's right and what's wrong.

Emil has become more and more withdrawn. He spends hours alone in his room, hardly speaks to us and seems to have lost interest in everything. He used to be full of life, with big plans and dreams. But now it's as if he's given up on himself. His therapist advises us not to let him go to public offices alone because he has difficulty organising himself - but how can we make him understand? He wants to show us that he has grown up, but then he withdraws completely. Sometimes we only find out afterwards that he had appointments or made important decisions. This uncertainty is hard to bear - we don't know if we should trust him or if we should be more supportive.

We are also burdened by the lack of information from the doctors. We have never really been clear about his exact diagnosis or the course of treatment. The doctors are reticent and we often feel abandoned by the professionals. Here is an example that really affected us: After a stay in hospital, which was initially good for him, his medication was changed and he got worse again. When I wanted to talk to the doctor, I was told that this was not possible for privacy reasons. It's the same story all the time - we come up against closed doors and feel helpless.

Our biggest fear is about the future. We keep asking ourselves: will he ever be able to lead an independent life? Will he ever be able to enjoy life again? Will he ever be the same warm, funny young man he was before? These thoughts keep me awake at night. At the same time, we struggle with the fear that he will fall back into old patterns and get involved with the wrong



people. We hope that a supported living environment might help him, but finding a suitable place is proving difficult. The waiting lists are long, and we are worried that he will deteriorate further in the meantime.

As a family, we are also struggling with the fact that we have changed so much. My husband and I have always done a lot for our children, travelling with them and lovingly looking after them. But Emil's illness sometimes gives us the feeling that we've done everything wrong. People who don't know us are quick to judge and label us as negligent parents. But we have always had a loving relationship with our children.

There are days when I can't take it anymore. I feel exhausted and wonder how much longer we can go on like this. Every moment of joy in our lives is overshadowed by the thought that Emil is not well. When occasionally we do things as a family together, I have a bad conscience. My psychologist keeps telling me that I need to live my life too - but how can I when my child is suffering?

Main topics covered in this story

Behaviour and disease manifestations of the son Emil:

Disorganised/Incoherent behaviour; Inactivity/Blunting

Experiences and emotions of the mother Veronika:

Distress; Other challenges; Appraisal of others; Positive attitudes of family member

Other main topics:

Physical health of family member/patient; Services and Professionals; Therapy-related issues; Stigma, Discrimination, Social network, Public realm; Legal issues and police involvement



37 Dorotea - a sister caring for her brother

Dorotea is the 33-year-old sister of her 26-year-old brother Christian, who had suffered from drug addiction for a long time before he was diagnosed with paranoid schizophrenia five years ago. Dorotea's story is dominated by Christian's past violence and continuing threats of violence against all family members, leading to constant fear, desperation and helplessness.

(54 words)

"Neither of us dares to do anything for fear he will go completely crazy"

I don't know what to do anymore. My brother Christian, who I used to admire so much, had been suffering from drug addiction for many years and had often been violent. A couple of years ago things escalated. He suddenly attacked a stranger in our town - for no reason at all. When the police arrived, he even attacked an officer. He was then taken to a psychiatric hospital, where he was diagnosed with paranoid schizophrenia. Finally, we had an explanation for his behaviour. We thought it was the first step towards recovery, but we were disappointed. He was discharged after a short time. The doctor told my dad that both the staff and the other patients were afraid of him.

Since then, we have been heading inexorably towards disaster. My brother refuses all forms of help and does not acknowledge how ill he really is. On my last birthday, the worst moment happened: he threatened my mother's husband with a knife. I had to use all my strength to stop him. It was then that I realised that we had long since lost control. We live in constant fear - never knowing when he will come back and what will happen next. We can't just ignore him, because he always finds a way to interfere with our lives. The uncertainty and constant threat wear us down.

My partner is particularly suffering from this situation. Every morning my brother waits outside his place of work, stares at him, puts him under psychological pressure. He knows how to instil fear in us. My partner has an important position in his company and a year ago my brother called the police and said my partner was stealing from the company. It turned out to be an unfounded lie, of course, but the damage was done. Now we live in constant fear that he will do something similar again. My partner is afraid to confront him for fear that another accusation will destroy his career forever.

We have called the police countless times. But they are powerless. As long as my brother doesn't hurt anyone seriously, they can't do anything. He knows the rules inside out, he knows how far he can go without getting arrested. He lurks outside my mother's flat, threatening her,





shouting, but always just below the line that would justify intervention. We don't know how much longer this can go on. Will it be too late at some stage?

My mother is now totally intimidated. She hardly leaves the house for fear of running into him in the street. He has already stood outside her door twice, shouting angrily into the hallway. I can't stand the sound of his voice, his threats. Sometimes I sit up at night and wonder how we will ever get out of this nightmare.

We are trapped in a vicious circle from which there seems to be no escape. Neither of us dares to do anything for fear that he will go completely crazy. He knows where we live and where my parents work. This constant threat wears us all down. We want to help him, but we don't know how. It feels like we're just waiting for the police to arrest him for missing dates of court hearings. Then maybe, just maybe, he'll finally get the help he so desperately needs. We want a solution more than anything - for us, but especially for my brother.

Main topics covered in this story

Behaviour and disease manifestations of the brother Christian:

Aggressive behaviour; Insight into illness/Compliance with therapy

Experiences and emotions of the sister Dorotea:

Distress; Other challenges

Other main topics:

Relationships within the family of the patient; Physical health of family member/patient; Services and Professionals; Legal issues and police involvement





38 Susanne - a mother caring for her son

Susanne is the 49-year-old mother of her 24-year-old son Benni who was diagnosed with schizophrenia at the age of 20. Susanne describes her husband's and her own despair when seeing Benni increasingly withdrawing into his own mental reality and also her attempts to hide Benni's disease from the outside world in order to avoid potential accusations that she and her husband haven't done the right thing. (66 words)

“People are always looking for someone to blame and assume it could never happen to them”

The diagnosis of schizophrenia of my older son Benni has turned our lives upside down. I worry about him all the time. Sometimes I see him moving his lips and acting nervously, as if he is not quite there. Then we pretend we haven't noticed, so as not to upset him. But it breaks my heart to see him like this.

I keep asking myself why this has happened to us. I had a difficult childhood with emotionally distant parents and all I ever wanted to do with my own children was to give them love and security. We have done so much to give them a good life and yet here we are - with all the worries, insecurities and fears.

My son has always been a loving and sensitive person, but since his illness it is as if the joy of life has been taken from him. His curiosity is gone, old hobbies and friends mean nothing to him. He often just lies in bed and seems to be miles away in his thoughts. Sometimes he doesn't leave the house for days, and when I try to motivate him to do something, he avoids me or reacts irritably. We often have to remind ourselves not to push him, but it's not easy. I often feel I can't help him no matter what I do.

One of the most difficult challenges is dealing with the outside world. In my job in the health services, my colleagues don't know about his illness. I'm afraid they'll judge us or feel sorry for us. People are always looking for someone to blame and assume it could never happen to them. But it can happen to anyone. I don't want to justify myself, but sometimes it feels like people don't believe we're doing our best.

His brother has distanced himself because he never understood why Benni ended up in this situation. He often says that he had so many opportunities and can't understand why he gave them up. My husband and I often lay in bed crying, wondering how to go on. At the same time, we had to appear strong to the outside world, especially to our younger son. This double burden has left us emotionally drained.





I try to be there for Benni, but it's difficult. We have been considering the idea of him moving into a supervised living arrangement for a long time. On the one hand, it would help him to get some structure back into his life, but on the other hand, we were afraid that he would see it as a rejection. But now he has agreed to it himself and we hope that he will feel more secure there and see that he can do a lot on his own. We have assured him that we will always be there for him and that he can always come home.

I try to look forward with confidence. My biggest wish is that one day he will find the joy in life again, that he can rebuild a better relationship with his brother and that we as a family can feel a bit more at ease. But the fear remains - of relapses, of the future and of our family never feeling the same again. I hope he gets the right help and that the disease doesn't get any worse. Life is not what it used to be and that hurts. But we're not giving up.

Main topics covered in this story

Behaviour and disease manifestations of the son Benni:

Inactivity/Blunting; Strange behaviour (not aggressive); Disease course

Experiences and emotions of the mother Susanne:

Distress; Care dilemma – more or less care and control; Other challenges; Appraisal of others; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Services and Professionals; Causal assumptions/theories; Stigma, Discrimination, Social network, Public realm





39 Melina - a daughter caring for her mother

Melina is 46 years old and the daughter of her 70-year-old mother Annetta who was diagnosed with schizophrenia when Melina was a baby. Melina describes her exhaustion due to her mother's steady erratic and contradictory behaviour such as first alarming Melina for help, then rejecting it, later complaining that Melina is not doing the right things, and finally pretending that there had not been a problem at all. Melina also reflects about several ways how to get relief by looking more after herself. (83 words)

“There are days when I get a call from her every hour, sometimes in the middle of the night”

My mother has lived with mental illness since I was born. I am now 46 years old, and the challenges of her illness have been with me all my life. My mother lives alone and for some time now she has consistently refused to take her medication. As a result, she calls me all the time, insults me and blames me, and a little bit later she calls again, apologises and acts as if nothing had happened. This constant change is exhausting and is taking a toll on my daily life and my emotional wellbeing.

I visited her recently. Her flat is chaotic, a clutter of yellowed newspapers, useless things and old memories. Despite several attempts to offer support, she categorically refuses any help. I have organised a panic button for her so that she could call for help in an emergency. But instead of accepting this, she misinterprets my efforts as control or paternalism. She recently told me that she is no longer my mother because I refuse to be her legal adult representative - a decision I have explained to her countless times and which I have made for my own protection.

I have been trying to come to terms with this situation for many years and have also undergone therapy to deal with my own childhood. I grew up in a boarding school because my mother already had mental health problems. She was in and out of institutions and hospitals. During these periods I often had hope that she could be stabilised in the long term. But she has been withdrawing more and more, cancelling appointments with social services and isolating herself more and more from the outside world. Her social contacts have almost completely broken down, which makes my concern all the greater.

The situation weighs heavily on me. There are days when I get a call from her every hour, sometimes in the middle of the night. In the morning, she is full of accusations and insults, and in the evening she apologises. This emotional rollercoaster often leaves me feeling helpless and increasingly exhausted.





My father, from whom my mother has been separated for a long time, keeps telling me to keep my distance. It was only when he called her recently and told her unmistakably not to contact me again that I was able to breathe for a few hours. But I still feel guilty. I keep wondering if she is all right and if she might hurt herself.

A few days ago, I received a call from her threatening to kill herself if I didn't come immediately. I immediately alerted all the necessary emergency services - police, ambulance and emergency doctor. A few hours later she was laughing on the phone with my father as if nothing had happened. This manipulative pressure is hard for me to bear. I have more than enough to do in my job, but these calls take all my energy.

I know I have to set limits, but the guilt is always with me. I keep trying to do something nice for her - small gestures like bringing her flowers or her favourite chocolate. But even that is questioned. She recently asked me if I had only given her a gift because I didn't like it myself. Her suspicion and how she distorts my intentions hurt me deeply and make it difficult for me to do anything good.

She continues to refuse all medication and medical treatment. This does not make the situation any easier. I try to cope with my own daily routine, but it is difficult for me when I am constantly under pressure and have to deal with these extreme mood swings. Even my own health suffers because I am always on alert and never really able to switch off.

Maybe it would help to be unavailable for a few weeks - and to communicate that clearly. Other people go on trips around the world for months at a time and are also away for a while. Maybe that would be a way for me to get some peace and distance and finally focus on my own life. I know that I can and must take this time for myself in order to stay healthy in the long term.

Main topics covered in this story

Behaviour and disease manifestations of the mother Annetta:

Inactivity/Blunting; Strange behaviour (not aggressive); Aggressive behaviour; Self-harm; Blaming; Insight into illness/Compliance with therapy

Experiences and emotions of the daughter Melina:

Distress; Positive attitudes of family member

Other main topics:

Services and Professionals; Therapy-related issues; Legal issues and police involvement





40 Tamara - a wife caring for her husband

For nine years Tamara (now 34 years old) has been living together with her 38-year-old partner Leander, who had received the diagnosis of “psychosis” at the age of 22, long before their relationship started. After his first “terrifying” psychotic breakdown during their relationship he took medication, and the situation was stable for a long time. Now they have a 14-month-old son and Leander is psychotic again after refusing medication. (69 words)

“The pressure of having to judge on my own whether my partner is capable of looking after our son is almost unbearable”

I have been living with my partner Leander for 9 years and 14 months ago we became parents of a wonderful son. Our small family means everything to me, but we always face big challenges. My partner has been suffering from psychotic episodes since he was a young man and the first episode had occurred long before our relationship started. He receives both psychiatric and psychotherapeutic treatment, but his attitude to his medication is problematic.

When I experienced the first psychotic episode during our relationship I was extremely upset and terrified. He was no longer the person I knew: he was completely changed and helpless. The experience left a deep impression on me. In many discussions, I made it clear that our relationship could only continue if he continued to take his medication, which was my safety net to provide stability for us as a couple and for him. For years he took his medication regularly and there were no further psychotic episodes.

A few weeks ago, I found out that he had stopped taking his pills without my knowledge. He said he felt better without them: no irritable bladder, less anxiety and fewer stressful thoughts. I understand that he finds the side effects annoying, but the fear of relapse immediately returned. The feeling that he could have another psychotic episode at any time hangs over me like a cloud.

And so, our arguments increased. Communication broke down time and again, and he reacted increasingly irritably to my concerns. I wondered if I could trust him alone with our son. Although he was always affectionate with him, I was always afraid: What if he is no longer grounded in reality? What if he suddenly lost touch with our son's needs? These thoughts didn't go away.

When I spoke to him about his changed behaviour and suggested that it might be a result of the drug withdrawal, he became angry. My insecurity grew. I had to work and felt uncomfortable leaving our child with him. Of course, he thought my worries were exaggerated and reproached





me severely. Nevertheless, I decided to ask my parents for help, and they ended up looking after our son.

In retrospect, that must have been the right decision, because he has become increasingly agitated, talking non-stop, but at the same time seeming strangely absent. He claims that this is his true personality, which has only been suppressed by the pills. I find this hard to believe, because I see a person in front of me who is no longer the person I knew. He seems to be in a constant battle with himself.

At the same time, our daily life has completely changed. Not only did Leander stop taking his medication, but he also made radical decisions in other areas. He changed therapists and began to look intensively at his past. At first this seemed like a positive step. He talked about wanting to be more assertive and finally articulate his needs more clearly. But this change quickly took on extreme features. He became self-centred, talked incessantly about his artistic achievements and I hardly got a chance to speak.

One of the most frightening incidents was when he fell out with my parents. Suddenly he was making unfounded accusations against my father, claiming that he might be violent. I was deeply affected by these statements because I knew they had no factual basis. Then, without warning, he spent twelve hours at a colleague's house, describing it as the best day he had had in years. I sat at home and worried because I didn't know where he was and why he was gone for so long.

These constant conflicts and his leaps of thought inevitably led to more arguments between us. He didn't want to see that I was worried. On top of that, he explained that he had saved all Email-messages with my parents - as if he was preparing for a conflict with them. I found these thoughts confused and was extremely stressed by them.

We will have another appointment with our couple therapist next week. I hope we can talk about our situation there and maybe I can find some support. The pressure of having to judge on my own whether my partner is capable of looking after our son is almost unbearable. I am constantly on guard, watching every change in his behaviour and wondering how long our relationship can withstand these stresses.

I want nothing more than for us to create a stable environment for our son. My partner has always had a wonderful relationship with him and it would be so sad if this were to be destroyed by his illness and the conflict over medication. But I know I cannot bear this responsibility alone. I need support and I hope that together we can find a way to restore security and a sense of normality for all of us.



Main topics covered in this story

Behaviour and disease manifestations of the husband Leander:

*Psychotic symptoms; Other psychopathological symptoms; Aggressive behaviour; Blaming;
Insight into illness/Compliance with therapy*

Experiences and emotions of the wife Tamara:

Distress; Other challenges; Appraisal of others

Other main topics:

*Relationships within the family of the patient; Physical health of family member/patient;
Services and Professionals; Therapy-related issues*



41 Cornelia - a mother caring for her son

Cornelia is the 72-year-old mother of Nils, who received the diagnosis of schizophrenia 24 years ago when he was 19. Cornelia lets the reader understand the difficult circumstances of the first psychiatric hospitalisation of her son, how she emotionally struggled with herself, being torn between feelings of guilt and relief. Today Nils has a daily routine, takes his medication regularly and has built up his independent life. (67 words)

"He told me that I shouldn't say a word on the whole way – we would be bugged"

My son Nils has always been a sensitive, thoughtful person, but nothing could have prepared me for what was yet to come in his life. From an early age, I felt that he was different – not worse or better than other children, just different. He was creative, but also fragile. For a long time, I didn't know exactly what was wrong with him until the first serious mental crises began. Now I know that a severe mental illness crept into our lives slowly and almost unnoticed. At first, there were phases of great anxiety, mood swings and withdrawal. But over time, his episodes became more intense. Particularly around Easter, there were repeated escalations.

When I first noticed that something more serious had developed, Nils was living in another city. I was supposed to pick him up on one of these Easter weekends. He sounded strange even on the phone. He told me that I shouldn't say a word on the whole way – we would be bugged. By the Russian secret service. I was stunned. I had never heard anything like this from him before. I knew that he used cannabis, and later hallucinogenic mushrooms. But this was a new dimension.

He told me that his friends at the time wanted to take him to a religious sect and that they wanted to do him harm. I knew these friends. I knew that they were harmless – except for the fact that they also took drugs. But for Nils, this was reality. Even today, almost 30 years later, he is still convinced that this is how it was back then. When I bring it up, I don't get a rational answer – just fear, anxiety, flashbacks.

At that point, I was already living on my own after splitting up with his father and I knew I couldn't handle it on my own anymore. I called my older daughter, Larissa. She was the one who made the decision: Nils had to go to the hospital. She organised the admission and took care of everything. It was Easter Saturday when he was admitted to a psychiatric ward for the first time. He was completely upset, and so was I.

We drove to the nearest psychiatric hospital in our private car. I was devastated. When I entered the building, I was overcome with a wave of feelings – fear, shame, relief. In the





country-side, people often say that someone belongs in '.....', naming the place where the psychiatric hospital is located – meant as a form of humiliation, as a devaluation. And now it was me who had to take her own son there. But at the same time, I felt a strange relief. I couldn't take it anymore, and here he was safe.

Nils was full of delusions. He kept asking me, 'Do you hear that too? You have to tell me that someone is there! I know for a fact that someone is listening to us!' I didn't know how to react to that. Should I tell him that there is no one there, or should I agree with him and fuel his fears even further?

Nils finally received the diagnosis of paranoid schizophrenia. The doctors explained to me that the disease usually develops insidiously, often in late adolescence. Looking back, it all suddenly made sense – the fears, the hallucinations, the phases of deep despair. But at the time, it felt like a stroke of fate.

I had always worked, which was perhaps my luck – because at least I had a small distraction. But every day was a struggle. A friend of mine regularly accompanied me to the hospital. She waited outside in the car while I visited Nils. She was my anchor during this time. That was exactly what I needed – someone outside of my family who would catch me when I fell.

After several stays in hospital, the next battle was to find the right therapy and the right medication. Nils kept stopping taking his medication, and kept having relapses. But over time, he learned to live with his illness. He graduated from school at the age of 21, and a year later he began therapy at a day clinic.

The turning point for him was moving into a therapeutic residential community with a structured daily routine, in which both those affected by schizophrenia and their relatives were involved in the healing process. He stayed there for a year and a half. Every week there was an evening for relatives, and we even had to stay there overnight once a month. That gave me strength – but it also robbed me of my energy. I did all this alongside my full-time job.

There Nils found a friend, Niklas. They became inseparable. Like Siamese twins. They couldn't be without each other. But Niklas' parents saw it differently. They blamed Nils for their son's lack of recovery. And yes, Nils may have introduced him to circles that weren't good for him. But Niklas was just as dependent on Nils as Nils was on him.

After the time in the therapeutic community, they first lived in a shared flat and then in a flat in Niklas' father's house – a seemingly good solution, but it didn't last. Niklas' mother did everything she could to separate them. In the end, Nils got a council flat. In theory, they were





now living separately. In practice, however, they spent every night together. The conflict with his mother weighed so heavily on Niklas that he broke off contact with her.

Shortly afterwards, Niklas took his own life. Nils found out about it via social media. The grief was overwhelming, but he never spoke about it. Perhaps because the pain was too great to process.

But my son didn't go the same way. He kept fighting, moved into his own apartment, got support from social workers and started building an independent life. Today he has a regular daily routine and takes his medication regularly. The difficult phases have become less frequent. I am proud of him.

Main topics covered in this story

Behaviour and disease manifestations of the son Nils:

Psychotic symptoms; Self-harm; Insight into illness/Compliance with therapy; Disease course

Experiences and emotions of the mother Cornelia:

Distress; Appraisal of others; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Physical health of family member/patient; Services and Professionals; Therapy-related issues; Information deficits; Stigma, Discrimination, Social network, Public realm





42 Albert - a brother caring for his brother

Albert is the 69-year-old brother of Heinrich, who is one year older and was diagnosed with schizophrenia 41 years ago, when he was 29, and both brothers were owning a shop and working there. Albert describes the yearlong process of Heinrich withdrawing from social relations until one day a psychotic episode broke out in public. Heinrich accompanied his brother over many decades with repeated psychiatric hospitalisations and is still supporting him. (71 words)

“I have learned to simply acknowledge his strange ideas”

My brother Heinrich and I come from a family of six children. Heinrich is the oldest, I am the second oldest. Even as a child, Heinrich stood out because he was not very active and always let others do things for him. My father had built up a successful household goods business in an Austrian provincial town in the south of the country and then did the same in Vienna, where we grew up. But he kept the shop in the provincial town. The Vienna shop was very successful, grew bigger and bigger and at some stage had ten employees.

After graduating from high school, Heinrich was employed in the Vienna shop, and I followed a little later. When my father died, we both became equal owners of the business and it went very well for many years. But there was always tension because Heinrich didn't get on with the staff and in the end, he just concentrated on the bookkeeping in the background. I didn't realise for a long time that he was making a lot of mistakes until one day we had the tax office in the shop and were notified of fines. Heinrich was very angry about it, felt unfairly treated and ran away.

As it turned out later, he had immediately taken the train to the other business in the province and had not continued at a transfer station, but had gone to a church. There he had started to cry and scream violently. He told a priest who tried to calm him down that someone was trying to poison him, but could not be calmed. The police and ambulance were called to the scene and he was taken to a nearby psychiatric hospital.

It turned out that he had apparently been developing a persecution complex for several years. He confided in me that he was being sexually abused by a shoemaker who had a shop near our store and that the cook at the restaurant across from our store, where he had always had his lunch, put poison in his food. He could hear the voice of a lawyer who was preparing a lawsuit against him. I have to say that I hadn't noticed any of this. It was only clear that he had withdrawn into a small room in the shop to do his bookkeeping and no longer spoke to anyone. It hadn't occurred to me that it was a mental illness.





After this incident, he returned to the business after some time. He told me that he was taking medication. He always trusted me, but not his siblings, who had broken off contact with him long before. I tried to burden him as little as possible with difficult tasks so that, without letting him notice, he had a protected workplace in some way.

It wasn't easy, but it worked for a few years until one day he started shouting on the street in front of the shop and accused the chef at the restaurant across the street of trying to poison him. He was admitted to a psychiatric hospital again. After his release, he told me that he was being irradiated in his apartment and that's why he had covered the walls with metal plates, which didn't help much though, as he said. When the house was sold, he had to rent a different apartment, which I helped him with and he willingly accepted the help. There too, he covered the walls with metal plates. He then moved out of this apartment as well because the metal plates didn't help. The same thing happened in the new apartment. He moved a total of six times. Sometimes he slept in the bathtub to be better protected from the radiation. Over the years he was repeatedly admitted to a psychiatric hospital.

The business was ultimately sold, and we are both retired today. In the meantime, I managed to persuade him to move into a sheltered housing facility. There he couldn't put metal plates on the walls, but because he is taking medication, he seems to accept this. We meet about once a month. I organise the meetings as uncomplicated as possible, and I do it this way: I know that he regularly goes to a church at certain times and sits there for hours, motionless, at a side altar. I then go there and just sit down next to him and we say almost nothing. That way, he knows that I am there for him, without me wanting to correct him about the delusions that he still has and occasionally expresses when we meet. I have learned to simply acknowledge his strange ideas.

Main topics covered in this story

Behaviour and disease manifestations of the brother Heinrich:

Psychotic symptoms; Inactivity/Blunting; Strange behaviour (not aggressive); Disease course

Experiences and emotions of the brother Albert:

Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Services and Professionals; Therapy-related issues; Stigma, Discrimination, Social network, Public realm; Legal issues and police involvement



43 Franz - a father caring for his son

Franz, currently 79 years old, is a retired GP and the father of his 44-year-old son Fritz, who was diagnosed with schizophrenia 15 years ago when he was 29. Franz describes his son's chaotic trip to Italy with many hospitalisations there, the continuing hallucinations and delusions of Fritz with frequent embarrassing behaviour in public. Attempts to get Fritz into a supported living facility have failed so far due to his continuing psychotic symptoms. (73 words)

"I have learned to accept what is difficult to change and try to make the best out of it"

I am a retired general practitioner, but I still work part-time in my private office. I am living together with my partner. For four years my son Fritz who suffers from schizophrenia has been living with us in the same flat (with an interruption of nine months when he lived at a supported living facility). Earlier he had lived with his mother (my ex-wife) for many years.

When Fritz started to study psychology at the University at the age of 19, he had sleeping problems, concentration difficulties and anxiety states, which my then wife and I interpreted as laziness. After 2 years he broke up his studies, worked part-time in several jobs and started a training as a fitness coach. He then went to Italy and lived there for 5 years, working part-time in student jobs, at hotels and fitness centres (he speaks perfect Italian).

In 2010 he came back from Italy in a full-blown psychotic state. He had delusions of persecution and was admitted to hospital immediately. Since then, he is in a chronic psychotic state with delusions and hallucinations. He developed a delusional identity as an Italian citizen with a different name and different parents and accused us, his parents, that we had kidnapped him at the age of 1 in Italy and brought him to Austria.

This uncorrectable delusion created a lot of tension between us. He developed other delusions, such as being persecuted by a Nazi Party in Italy, and the "grandiose" delusion of being the owner of the Italian railway company. For instance, he went by train to Italy without a ticket and argued at a ticket-control that he was the owner of the Italian railway company and does not have to pay, and was then brought to a psychiatric hospital ward by the police. He also said that he was married in Italy and had children there and that he would get regular income from Italian companies. He went several times to Italy and was several times admitted to hospital there, and I had to go there and bring him home.



We tried hard to organize rehabilitation activities for him in Austria, but he refused day-structure activities and hostels with the argument that he had no time for it. He developed his own day structure with daily training at a fitness-club or going to a swimming pool. He developed the delusion that he was a news speaker at an Italian broadcasting company and began to speak news in Italian language several times per day into his mobile phone. This he does until now. There are days, however, when he lies in bed all day and reflects his life as miserable. He is socially withdrawn, has only contacts with me and his mother and some superficial contacts at the fitness club.

I managed at some stages of the illness that he agreed to take oral antipsychotic medication. Sometimes there was a lack of compliance because of severe side effects. Since some years compliance is much better since he also gets depot-medication.

Several years ago, his mother bought a flat where he could live on his own, and we organized weekly visits from staff of a community mental health service. After a few weeks this setting failed, because Fritz developed paranoid ideas on his neighbours in the house and called the police because he thought his wife from Italy was raped there. The police visited and questioned the neighbours (also at their working-place!!!) and this made it impossible for him to stay there longer. He was hospitalized and afterwards I took him into my flat. He had made similar accusations also in restaurants and in coffee shops.

When living with me he also called the police about rapes and murder in other flats, but after I had discussions with the neighbours about his illness the situation calmed down. I had told them to watch out for any early warning signs of his illness and gave all of them my telephone number. I was lucky because all neighbours liked him, and he usually was very friendly to them.

Nevertheless, I tried to find him a place in a supervised hostel for mentally ill people. I was successful and he agreed to go there. There he had difficulties to socialize with the other residents. In the beginning he refused to participate in the weekly group sessions and leisure time activities. As nobody had an eye on his daily oral neuroleptic medication (additionally to his depot injection) his compliance was lacking, and psychotic tension was increasing.

He had several psychotic outbursts with shouting in the house and out of the window to the street. Once he threw a glass bottle out of the window into the house opposite and smashed a window there. The owner of the hostel house demanded that he had to leave otherwise the contract for the whole hostel would be terminated. When he had lived with his mother something similar had happened, as he once threw a flower box out of the window on a parking





car, which belonged to one of the neighbours in the house. So, the neighbours did not accept that he would stay further in the house.

After a longer inpatient stay in a psychiatric inpatient department, he came back again to my flat and is living now with me and my partner. There is often tension between us, because we have different views about cleanliness and order (washing dishes in time, cleaning the floor, ventilating the room, taking out the dung bucket, etc...), which makes life stressful for me, but I have learned to accept what is difficult to change and try to make the best out of the situation.

I regularly control his medication, remind him when he forgets to take it or when he gets confused about the date (medication is packed in a box for each day of a whole week). It seems that for him it is important to find somebody when he comes home every day to the flat just to say hello and speak a few words and otherwise not to be disturbed in his room (he gets anxious when we leave for more than a few days, although his mother meets him several times a week). We are still looking for a sustainable living solution for him, and he is actually on waiting lists of several hostels.

Main topics covered in this story

Behaviour and disease manifestations of the son Fritz:

Psychotic symptoms; Inactivity/Blunting; Other psychopathological symptoms; Strange behaviour (not aggressive); Aggressive behaviour; Insight into illness/Compliance with therapy; Disease course

Experiences and emotions of the father Franz:

Care dilemma – more or less care and control; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Physical health of family member/patient; Services and Professionals; Therapy-related issues; Causal assumptions/theories; Stigma, Discrimination, Social network, Public realm; Legal issues and police involvement



44 Gudrun - a mother caring for her son

Gudrun is the 68-year-old mother of Matteo, who is 42 years old and was diagnosed with schizophrenia at the age of 18. Gudrun focuses on Matteo's efforts to build up his own life and become independent despite his disease. She describes how he has managed to live in a partnership and get on to part-time jobs to improve his financial situation on top of his disability pension. (67 words)

“Matteo struggles to find a way to live with his illness without letting it control him”

Already as a child, my son Matteo displayed behaviours that worried me. He was not like other children. He often withdrew, was in his own world and had difficulty focusing on the essentials. Teachers kept telling me that he had to try harder and that he would be fine, but I felt there was something else going on inside him and that it was not just laziness.

As he grew older, the suspicion that there was more to his difficulties finally led to the diagnosis of schizophrenia. The word hit me like a blow. What does this mean for him? For us as a family? For me as a mother? I just knew that I wanted to accompany him, but I had no idea what this path would look like.

The following years were characterised by struggle and a lack of understanding. Matteo kept going through phases of euphoria, followed by deep lows. Sometimes he was a different person. At some moments, he saw the world in a way that was incomprehensible to us. During these times, the consumption of substances was also a problem – he sought a way out in drugs and alcohol to cope with the constant changes in his mind. But I knew that it wasn't doing him any good, and it always led to conflicts when I spoke to him about it.

Despite his difficulties, Matteo always felt the need to build something. He wanted to live a normal life, wanted to work, have a future. He started an apprenticeship in administration. I still remember exactly how he proudly showed me his certificate. I was so happy and proud of him, even though I knew that he had only just managed it with an enormous amount of effort and against many internal obstacles.

Starting his career was not easy. He repeatedly tried to gain a foothold in various jobs. But somehow none of the jobs lasted long. The stress, the high demands and the constant insecurity that his illness brings with it do not make it easy for him. Nevertheless, he continues



to fight. He now receives a disability pension that provides him with financial stability – but he doesn't want to rely on it alone. He took on a few part-time jobs in the hope of becoming self-employed, even though these jobs repeatedly push him to his limits.

Hoping for a more meaningful task, he decided to train as an assistant nurse. But the work in a nursing home became a burden. He was affected by the lack of appreciation from his colleagues, and after six months he stopped working there – another setback. Nevertheless, he did not give up altogether. Today he has two part-time jobs. Here, too, he repeatedly reaches his limit, but his desire for independence drives him forward. He is looking for his own way – even if that means constantly having to reinvent himself.

Matteo got married a year and a half ago. The marriage was another step on his long journey. But the relationship is also characterised by many challenges, and often I have the feeling that also his wife has mental health problems – which doesn't make the situation any easier. Nevertheless, he reflects on his situation well, he talks to his therapist weekly, and that helps him deal with the stresses.

His psychotherapy is a constant in his life. I see the progress, even if it sometimes only comes in small steps. But for me as a mother, it is a great relief to see that Matteo no longer comes to me with crisis situations, but has the right people to turn to. I have learned to trust that he can help himself – even if he is often unsure whether he is taking the right path.

He is always in conflict with himself – especially when it comes to his professional future. He recently had a hearing and was accepted as a “peer specialist”, a new profession, where people who have experienced a mental illness, assist other patients. But the thought of working in this job also scares him. He fears that the stress would affect him even more, and at the same time he needs the income to make ends meet. In moments like these, he looks to me for reassurance – but how can I tell him what to do when I don't know myself?

Sometimes it feels like we're both caught in a cycle of responsibility and fear. I know that as a mother I will always be there for him. But I also have my own limits. I can't be responsible for everything, and yet I often feel like I have to be. He asks a lot of me – and sometimes I take the liberty of saying ‘no’. I've learned not to feel guilty about it right away.

I know that Matteo is still searching for a way despite everything. It is not the way I had hoped for him, but he is taking it. Step by step. Even if it is difficult, there is progress. And that is what I want for him – that he also achieves small victories for himself in the midst of all his challenges and struggles. That he finds a way to live with his illness without letting it control him.





I have learnt to deal with the situation. To accept that I can't control everything, that I don't have the solutions to all his problems. But I am there, and that's what matters.

Main topics covered in this story

Behaviour and disease manifestations of the son Matteo:

Psychotic symptoms; Other psychopathological symptoms; Being stressed by external factors;

Disease course

Experiences and emotions of the mother Gudrun:

Distress; Care dilemma – more or less care and control; Appraisal of others; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Physical health of family member/patient; Therapy-related issues



45 Petra - a mother caring for her son

Petra is the 46-year-old mother of 26-year-old Finn, who was diagnosed with schizophrenia 5 years ago. Petra describes vividly how - after many years of stability due to treatment - Finn stopped his medication and led himself and the whole family into turmoil and conflicts. Recently, however, the situation has somewhat calmed down. (53 words)

“I am unsure how much I should point out the reality from my point of view or leave him in his own truth”

After my son Finn had received the diagnosis of schizophrenia at the age of 21, he had agreed to take medication and was doing well for several years. He lived with his girlfriend with whom he had a loving relationship, and we also got on very well together.

One year ago, his girlfriend called me, because she had perceived changes in him that I had also noticed. He seemed confused, talked incoherently and could hardly be stopped. He said that - in agreement with his doctor - he had started reducing the dose of his medication with the aim of stopping it altogether. At an appointment with his doctor, his critical condition was apparently not noticed or Finn was able to hide it well. Afterwards, he told us that the doctor had allowed him to stop the medication completely.

The consequences were catastrophic: He got confused, he digressed from one topic to the next and expressed irrational fears about technological issues. He was restless and slept less than before. Occasionally, he also became verbally aggressive. It was unpredictable, what he had in mind at the next moment and he needed a lot of attention.

My husband and I together with his girlfriend were able to convey to him that we were very worried. He seemed to feel, at least in part, that something was wrong, so he went with us to the emergency room. He spoke with a doctor alone at first, but my husband was allowed to join later. Medication was reinstated, and a follow-up appointment was arranged.

Shortly afterwards, his girlfriend and I accompanied him to the doctor again, although at first, he didn't want us to be there. The doctor confirmed that he was experiencing a psychotic episode and increased the medication dose further. Finn filled the prescription and, after talking to us, decided to go to his aunt's holiday home in the countryside to “calm down”. His



autonomy is very important to him, so I agreed. He called twice to say he was doing well, but we realized that he was still confused.

My husband and I had planned a three-week holiday and hoped that the situation would stabilise by then. His girlfriend and our daughter were ready to support him during our absence. Unfortunately, everything continued to deteriorate, and we cancelled our trip.

Medication remained the dominant topic. Finn only took it irregularly and – contrary to the previous years - had no insight into his illness anymore. When asked, he always emphasised that he was doing very well. Then he broke up with his girlfriend and moved back in with us. He needed to talk a lot and demanded a lot of attention. In our absence, he often took care of the cats, but he scared away his brother and aunt because he placed a great deal of importance on being treated as an adult, but he didn't always respect the boundaries of others. He found it difficult to keep things tidy.

He showed particular resistance to my husband's attempts to talk with him. He often and provoked my husband, who either reacted with anger or tried to withdraw. I constantly found myself in the role of mediator, calming my husband and trying to keep my son in a good mood so that he would not make any serious wrong decisions.

Fortunately, meanwhile Finn no longer appears acutely psychotic. It is now relatively easy to talk to him, but he rejects the terms 'psychosis' or 'disease' for himself. Instead, he describes himself as "neurodiverse", which I accept. At best, he says that he has had psychotic symptoms. He no longer takes medication. However he takes CBD, which he considers a natural remedy.

I am unsure how much I should point out to him the reality from my point of view or leave him in his own truth. He does not want to be labelled as sick, takes refuge in "his realities" and sees himself as an artist. The question of whether and how I should suggest that he take medication again without causing a major conflict is of great concern to me. So far, I see little chance of achieving this without an argument.

Main topics covered in this story

Behaviour and disease manifestations of the son Finn:

Psychotic symptoms; Disorganised/Incoherent behaviour; Inactivity/Blunting; Other psychopathological symptoms; Aggressive behaviour; Insight into illness/Compliance with therapy; Being stressed by external factors





Stories of Care

Navigating mental illness together

Experiences and emotions of the mother Petra:

Distress; Care dilemma – more or less care and control; Patient moves out of/back to the family home

Other main topics:

Relationships within the family of the patient; Physical health of family member/patient; Services and Professionals; Therapy-related issues



46 Konrad - a father caring for his son

Konrad is the 64-year-old father of Patrick who is currently 20 years old and was diagnosed with schizophrenia two years ago. Konrad describes in detail how he misinterpreted early signs of the disease as puberty crisis connected to cannabis use, how this was played down by drug counselling services and still struggles with feelings of guilt to have waited too long to ask for psychiatric advice. (66 words)

“It feels relieving when you no longer have to hide the truth”

When our son Patrick was 16 years old, we went to a counselling centre to talk about him starting to use drugs. The counsellor just said, ‘Don't worry, almost everyone smokes pot at that age. It will go away. It's quite normal these days, and cannabis will soon be legal anyway.’ We couldn't understand these statements. A few months later, we sought a second opinion. This time our son was also present. It was said that his consumption was not particularly high and that he was rather experimenting. We were referred to another institution that specialised in “minor consumers” – the same place we had visited first.

From that point on, we tried not to look at the situation too closely, as we had been advised to do. Today we know that this was a mistake. Our son also blames us for this: ‘You just let me do it, and now I'm suddenly supposed to stop?’ We understand that these are often just excuses to blame us for the addiction, but it still leaves a bitter aftertaste.

Then things got really bad. His drug use increased more and more, his motivation to continue with his apprenticeship and his performance at vocational school dropped drastically. He withdrew further and further into ‘his own world’. At first, we thought it was just puberty. Looking back today this was probably the first sign of a beginning mental illness.

His days became increasingly strange. We tried to leave him alone and live a normal life. He got up in the morning or mid-morning, sat in front of the TV or on his phone. Sometimes he was just out walking for hours. He occasionally had lunch or dinner with us. There were no arguments during this time, and it almost seemed as if he wanted to avoid arguments as well. Nevertheless, the feeling in his presence was strange. It's hard to describe, but I often felt like fighting against the situation inwardly – and I still do.



We finally could convince Patrick to come with us to see a psychiatrist, and we were deeply shocked when we heard that he suffered from schizophrenia. Patrick agreed to be admitted to a psychiatric hospital ward, from where he was discharged after six weeks, with planned outpatient contacts.

When he came home, Patrick was somewhat more communicative, but didn't want to take the medication he was prescribed. He said it made him 'no longer himself'. To avoid arguments, we let him do it. He blames us for that today: 'You let me do it, so why should I do it differently now?'

These accusations are hard to bear and I took it all very much to heart. You want to do everything right, especially with your own children. Of course, you have to address certain issues. I'm very careful about how I do that because I'm afraid of being misunderstood or of being blamed. It weighs on me to be seen as the bad guy over and over again.

Looking back, the worst part was and still is this feeling of powerlessness. You want to help, but you just can't. This helplessness is incredibly difficult to bear. On top of that, there is also the feeling of failure. Although we always did our best, you constantly ask yourself, 'What did we do wrong? What should we have done differently?'

In the early years, we all really tried to talk ourselves out of it. With family and friends, we always said everything was 'so great' and, of course, our son was 'so well-behaved'. We just didn't want to admit that something wasn't going according to plan. We have left that phase behind us. Our family and closest friends now know what is going on, and that has made a lot of things easier. It feels relieving when you no longer have to hide the truth.

I currently discuss our problems almost exclusively with my psychotherapist or write down my thoughts – as I am doing here and now. Not because my friends wouldn't listen to me – on the contrary, they would support us at any time – but the feeling of shame is just too great. I am ashamed of the situation, even though I know I shouldn't be.

Sometimes, though, I do have moments when I can talk openly with friends. In these conversations, it feels right and good. Nevertheless, the question remains as to how we as a family can continue to deal with it and how we can continue to support our son on his path despite all the challenges.

Main topics covered in this story





Behaviour and disease manifestations of the son Patrick:

Inactivity/Blunting; Strange behaviour (not aggressive); Blaming; Insight into illness/Compliance with therapy

Experiences and emotions of the father Konrad:

Distress; Appraisal of others; Positive attitudes of family member

Other main topics:

Employment, Education, Finances of family member and patient; Physical health of family member/patient; Services and Professionals; Causal assumptions/theories; Stigma, Discrimination, Social network, Public realm



47 Alice - a sister caring for her brother

Alice is the 27-year-old sister of Victor, who is 24 years old and was diagnosed with schizophrenia 6 months ago. She describes how her brother increasingly behaved strangely after a serious accident which kept him in bed several months, how he developed ideas of persecution, was confused in his thinking and moved out of the family home, with only occasionally contacting his sister but refusing help. (66 words)

“Unfortunately, he refuses any further support”

The last year has been a challenging and worrying time for our family. It all started with a serious accident. After an evening of drinking alcohol and smoking cannabis, my brother Victor fell down a flight of stairs near his parents' house at around four o'clock in the morning. He only managed to drag himself home hours later. He had sustained multiple injuries, including a fractured vertebra and serious knee injuries. These required immediate surgery, and the subsequent rehabilitation period kept him in bed even longer. For my brother, who was always active and passionate about cycling, this time was particularly difficult.

When asked how the accident had happened, he initially said he couldn't remember. Later he said he hoped he hadn't done it on purpose, but he wasn't sure. After he was able to walk again, he stayed with friends in Rome for a few months and then came back.

Then we spent a holiday together as a family – parents, siblings and the partner of a brother. It was the first time in months that I saw my brother for a longer period. He seemed distant and hardly spoke to us. He only opened up to me sometimes.

One evening I found him crying in the garden. He said he felt like a stranger in his own family and no longer recognised the people who had raised him. He hadn't been able to sleep that first night. He told me that he had written a letter that he wanted to read to all of us, but was afraid that its contents would hurt us. In the end, he only read it to me.

Among other things, it said that he hoped our parents had never poisoned his food because he always got sick when he was at home. I tried to reassure him and asked if he wouldn't want to seek professional help. But he said his friends and cannabis were his therapy. ‘Our parents would do better to seek help themselves,’ he said.



He was hardly ever seen at home, only coming home to sleep and otherwise constantly on the move. Our parents hardly saw him. When he recently wanted to travel to another city, we arranged to meet at the train station in my city because he had to change trains there. I noticed something was wrong as soon as I arrived at the station. He was wearing a hoodie and a cap pulled down over his face and just said, 'Come on, we'll just go straight ahead, don't turn around.' His gaze was strange.

When I asked when his train was leaving, he said he might take it tomorrow after all. I invited him to my place, and there he asked my partner if he could check his mobile phone because he thought it had been hacked, and he needed an untraceable SIM card. His behaviour was erratic, his thoughts seemed confused, and he trembled slightly.

I asked him if he wouldn't mind talking to a psychologist. He refused and argued that he would overburden the psychologist and only 'break his sick shit' with him. He just said it was quite normal for him to be confused because he was at a turning point in his life. He finally wanted to move out of the family home and be independent, but had not yet made it financially.

The situation continued to deteriorate and our parents finally convinced him to see a psychiatrist. After several appointments, it turned out that he suffered from paranoid schizophrenia. This diagnosis helped us to better understand many of his behaviours, even though it was very painful to accept.

Unfortunately, he refused any further support and moved out of the family home. Since then, he has only sporadically contacted us and written that he is fine and wants to take care of himself. We hope that he will soon be ready to accept professional help. As a family, we want to show him that we are there for him without pressurizing him. It is important that he gets the time and space he needs to make independent decisions and gradually move in the right direction, even if that road may be a long one.

Main topics covered in this story

Behaviour and disease manifestations of the brother Victor:

Psychotic symptoms; Disorganised/Incoherent behaviour; Inactivity/Blunting; Other psychopathological symptoms; Strange behaviour (not aggressive); Self-harm

Experiences and emotions of the sister Alice:

Distress; Positive attitudes of family member; Patient moves out of/back to the family home

Other main topics:

Physical health of family member/patient; Services and Professionals



48 Hans - a father caring for his son

Hans is the 70-year-old father of Erik, now 36 years old, who suddenly stopped working when he was 17 and increasingly withdrew into his own world, hardly speaking with other family members and was diagnosed with schizophrenia at the age of 19. Hans describes the family's decade-long process of coming to grips with this situation. (55 words)

“There are still challenges, but also many good days – and that is a great benefit to us”

My son Erik is 36 years old and suffers from a mental illness. It's hard to say exactly when it all began, but when he turned 17, our lives changed dramatically. He had started an apprenticeship as a bookseller, but from one day to the next, he stopped going to work. He became more and more withdrawn, hardly spoke to us and seemed to live in a different world. We were never able to find out exactly what triggered it or whether it had been developing over years.

As parents, we were completely overwhelmed at the time. Instead of asking ourselves the most important question – how is our son? – our thoughts revolved around something completely different: how will we look? What will people say? We were ashamed, afraid of stigmatisation and didn't know how to deal with the situation.

I remember that we perceived Erik's condition not as a serious problem at the time, but as a kind of rebellion, a temporary lapse. It was only much later that I realised that we had hesitated for far too long to seek help.

Not only he, but the whole family was caught up in the situation. My wife, our two daughters and I – we were all speechless. We literally had no words to describe what was happening. We didn't know how to talk about it, either with each other or with others. This silence made it almost impossible for us to seek support. We hoped that everything would somehow sort itself out. But it didn't.

Erik ended up just staying at home. We lived parallel lives, often in tense silence. It was as if we were in two separate worlds – we in ours, full of worries and incomprehension, and he in his, to which we couldn't find access. The few conversations that took place often ended in arguments. The anger we felt at the time was directed in all directions – against him, against ourselves, against life.



At the time, I kept hearing about mental illness in the media, but I never thought it could affect us. However, over time, I started to look into the subject more and it slowly dawned on me that Erik's behaviour might be due to an illness. In the end, it was I who sought help. I turned to a psychosocial counselling centre, hoping to get some kind of guidance. There I was advised to suggest a legal guardianship for Erik – a step that should help us to clarify his legal and financial affairs.

Erik got a legal guardian who supported us and put us in touch with professionals to take care of Erik. But he rejected any form of help. The professionals who came to see us regularly tried to talk to him, but he refused to communicate. He didn't let anyone get close to him, he closed himself off completely. The visits therefore became more and more of a support for us parents – less so for Erik himself.

My wife didn't want to visit any self-help groups. She said she couldn't bear to hear so many sad stories because it would burden her even more. I, on the other hand, regularly visited self-help groups for relatives of mentally ill people. There I learned a lot about Erik's possible illness, but hardly anything changed in our everyday lives.

A turning point came when Erik had to take a medical examination for checking whether he was fit for entering the army. He had applied for "alternative" community service, and was assigned to an institution for disabled children – a task he didn't want to do under any circumstances. So, I called the institution, described our family situation, and shortly afterwards we received a letter: Erik was permanently exempted from military service and "alternative" community service. At that moment, we felt a great sense of relief – the problem had solved itself without us having to fight.

At the same time, there were a few appointments with the psychosocial service. Since Erik did not talk to the psychiatrists, a tentative diagnosis of schizophrenia was eventually made. For the first time, we heard the word schizophrenia in connection with our son.

Years passed. We lived in a large apartment, which allowed us to avoid each other. This made our life together more bearable. We got used to the situation – or rather, we were satisfied with it. For a long time, Erik had neither health insurance nor financial support. But his guardian was finally able to sort everything out. He received basic financial benefit, and had health-insurance through me. This security took a great burden off our shoulders.

Over the years, a certain stability emerged. He lived by his own rules, and we came to terms with that. Erik developed fixed routines that gave him security. He watched a lot of TV, was interested in various topics and began to open up a little to his surroundings again.





Even though he still goes his own way and big changes happen in small steps, we as a family have learned how to deal with it. Today, we live together in an orderly way, with everyone having their place. There are still challenges, but also many good days – and that is a great benefit for us.

Main topics covered in this story

Behaviour and disease manifestations of the son Erik:

Inactivity/Blunting

Experiences and emotions of the father Hans:

Distress; Positive attitudes of family member

Other main topics:

Relationships within the family of the patient; Employment, Education, Finances of family member and patient; Services and Professionals; Causal assumptions/theories; Stigma, Discrimination, Social network, Public realm; Legal issues and police involvement





49 Jochen - a father caring for his son

Jochen is the 66-year-old father of Max, who is now 36 years old, had been diagnosed with schizophrenia at the age of 16, and has been living in his family home until today. Jochen thoughtfully describes, how, after the sudden death of his wife 8 years ago, he was forced to reorganise his and his son's daily routine and how he managed to create an accepting environment by becoming sensitive to small communication signals of his son, leading to a way of living together that works for both of them. (90 words)

"I know that our relationship doesn't have to be perfect to be good"

When I retired six years ago, I knew that my life would not change suddenly. My daily life would continue to be shaped by the situation with my son Max. He is now 38 years old and lives with schizophrenia, a diagnosis that has dominated our family life since he was a teenager. For a long time, I didn't know how to deal with it. We often, lived more side-by-side than in real contact.

But eight years ago, everything changed abruptly. My wife died unexpectedly – a loss that not only affected me but also Max. Suddenly, I was solely responsible for the household. I had to cook, shop, and organise the things that my wife used to take care of. At first, I felt overwhelmed, but over time, I realised how important these everyday routines are. They gave me stability – and they helped me to rethink my relationship with Max.

Max was often aggressive towards me. He would swear at me, accuse me of things, yell at me and sometimes even physically attack me. For far too long, I tried, to reason with him – until I realised that it wasn't working. At some point, I just started walking away in such moments. I left the room, the apartment. Once I even moved out for a month and lived in a small holiday apartment nearby. That was good for both of us. It created the distance that was necessary to get closer again.

Over time, our life together became calmer. I learned that there was no point in fighting against his peculiar behaviour. For example, I kept getting him clothes, but he ignored them. It was only after months, when his old clothes were completely worn out, that he started to wear the new ones. I accepted that he had his own rhythm. So, I stopped pushing him and just made offers instead. I put a leaflet of clothes on the table and said nothing. A week later, he suddenly mentioned: 'Those blue shoes you could' He didn't finish the sentence, but I understood.





Gifts were also a difficult topic for a long time. I got him some for Christmas or his birthday, but he just didn't unwrap them. At some point, I stopped – and that's exactly what made him complain that he wasn't getting anything anymore. All at his own pace.

An unexpected form of communication developed through stuffed animals. He had had a collection since he was a child, and at some point, I noticed that he deliberately incorporated them into his everyday life. When watching TV, he placed them next to him on the armchair, as if they were watching with him. Sometimes he even made them talk when we were watching a football game. And then one morning I discovered a new kind of message: a stuffed animal was sitting on the kitchen table, holding a small note in its arms with the words, 'Oh, wouldn't that be nice, a sweet omelette today, smack.' At first, I thought it was strange, but then I realised that it was his way of communicating with me. And suddenly our interaction felt easier.

I also changed during this time. After my retirement, I started doing volunteer work, and an older lady I looked after introduced me to Qigong. What initially began as physical exercise became a whole new approach to life for me. The Chinese philosophy of Yin and Yang – the idea that opposites belong together and form a balance – helped me to better understand my own situation. I stopped fighting. Instead, I began to take things as they are.

Talking to a life coach also helped me. She repeatedly reminded me to take care of myself and to think positively. I never felt that I was being punished or disadvantaged for my situation – but it helped me to accept it more consciously.

Today, Max and I have found a way of living together that works for us. It is not 'normal' in the usual sense, but it doesn't have to be. Our daily life has its own little rituals. And even if we often don't talk to each other directly, we always find ways to communicate – be it through a stuffed bear that delivers a wish to me or through a football game that we watch together.

I couldn't have imagined in the past that our relationship could be like this. But now I know that it doesn't have to be perfect to be good.

Main topics covered in this story

Behaviour and disease manifestations of the son Max:

Strange behaviour (not aggressive); Aggressive behaviour; Blaming; Being stressed by external factors; Disease course

Experiences and emotions of the father Jochen:

Distress; Care dilemma – more or less care and control; Appraisal of others; Positive attitudes of family member



50 Ludwig - a father caring for his son

Ludwig is the 69-year-old father of Philipp, now 37 years old, who was diagnosed with schizophrenia at the age of 17 and still lives in his family home. Ludwig focuses on how his relationship with Philipp improved over the years, by learning to be less "therapeutic" and more accepting, and illustrates his change of attitude with several telling examples. (59 words)

"The biggest change I have noticed in myself is that I no longer always try to be right"

My son Philipp has been living with the diagnosis of schizophrenia for many years now and I have thought a lot about what it means to live in such a difficult situation and how it can change you. In recent years, I have learned that it does not simply mean seeing my life and that of my son as separate worlds. For a long time, I thought that I as a healthy person was somehow superior to him, but that has changed. I have now understood that we are both part of the same reality, and I have realised that I play just as much of a role as he does. If I change my attitude, the whole dynamic between us changes.

When I talked to Philipp a feeling of alienation often came into the room. I used to try to reason with him, to show him what he should do, how he could change. But gradually I realised that this constant struggle was getting me nowhere. I thought I had to take on some kind of therapeutic role, but I learned that sometimes it's much more important to just be myself, without constantly analysing and helping.

I remember an eye-opening episode a few months ago. Philipp wanted something to eat at night, as he often does. In the past, I might have refused or complained because it was an unreasonable time in my eyes. But at that moment, I decided otherwise. I just cooked him what he wanted without thinking. It was just a moment we shared, without discussion. It may have been just a small thing, but for me it was a step that showed I had become much more cooperative.

The biggest change I have noticed in myself is that I no longer always try to be right. It is no longer about arguing about who won, but about how we can get through life a little better together. And that has helped us to grow closer again as father and son, even if our conversations don't always revolve around big, deep topics.



It is often these small, almost inconspicuous steps that help us to move forward. We have often talked while going for a walk recently, and there were these moments when Philipp suddenly started talking to strangers – perhaps after years of barely exchanging a word. It was a trivial question about the way, but for me it was a clear sign that he hadn't completely disappeared into his own world. It was as if he was freeing himself a little more from his isolation.

And then there was the story with the signature. Philipp was confronted with a postman who asked him to sign for something. At first, he didn't know how to use the phone the postman held out to him. But then he showed a willingness to cooperate when he was told what to do. It was a small step for him – but it was a big one for me. It showed me that he is still able to interact with the world around him, even when everyday things challenge him.

It is these moments that remind me of the importance of recognising the small steps forward. The big, dramatic changes are rare and not always immediately visible, but every little change counts. I have learned that it is not just about exchanging words or actions, but also about understanding and patience. Maybe the steps are slower, but they are real. And that is what matters.

Main topics covered in this story

Experiences and emotions of the father Ludwig:

Care dilemma – more or less care and control; Appraisal of others; Positive attitudes of family member





51 Mariana - a mother caring for her daughter

Mariana is the 79-year-old mother of her daughter Alexandra who is now 45 years old and was diagnosed with schizophrenia 20 years ago at the age of 25. Mariana describes in detail how Alexandra's illness is complicated by excessive alcohol consumption, illustrates the difficult and stressful situation for the whole family by focussing on recent psychotic episodes and ends with a pessimistic stance of considering the situation when she will no longer be able to care anymore for Alexandra. (79 words)

"I believe that patients who have only elderly caregivers face permanent existential stress"

For the past two decades most of my time has been devoted to caring for my daughter Alexandra who has been hospitalized for schizophrenia many times since she was a young woman. It is a long story of problems and exhaustion, but I will focus here on events in recent years to illustrate the difficult and stressful situations you may experience as a mother.

A year ago, Alexandra was admitted to a psychiatric hospital three times; for two of these three admissions, she had called the ambulance herself. At the second admission I was surprised to discover in her room a rope hanging from the chandelier and a household ladder next to it. She said that she had not prepared these things for suicide but rather as an escape route for the moment when the people who she hears constantly threatening her would come to kill her "using advanced technology."

The fact that she goes through such psychotic situations, dominated by fear and voices, is overwhelming for me. How can a mother sleep in such situations?! Emotionally, I go through extreme stress. Being a rational person, I always find the strength to move forward and provide for the family's needs concerning food, medication, cleanliness, etc. but it's not enough. Maybe I need to go through adequate psychotherapy myself to learn how to interact with Alexandra.

The problem is not only the recurrent worsening of her symptoms, but also the complication caused by her alcohol consumption in recent years - up to 3 to 5 litres of beer per day.

This year, the month of August was an inferno for the whole family. Alexandra's computer – which she used to surf the internet starting at 2 in the morning while drinking coffee and smoking a lot of cigarettes - broke down; perhaps she was also decompensated due to extreme heat. Very noisy days begun, with a high consumption of beer and a lot of energy spent on delivering absurd speeches.





These days were followed by days where she restrained from alcohol consumption and was totally exhausted. I put everything aside and stood by her for hours and in this way, I managed to help her control her aberrant associations and her exaggerated superstitions - she believed everyone hated her and wanted her to die.

I decided to take her to a psychiatric hospital - it wasn't easy, at first, she resisted, but my husband managed to convince her. She was discharged after three weeks. Her medication had been adjusted, and having left the home environment for a few days was good for her.

Upon her return home, she resumed her habit of drinking a lot of coffee at night; she refused medication, drank again lots of alcohol. A few days later we found ourselves with the ambulance at the door. She had called them without telling us because she "felt sick in her head". She was again admitted to a psychiatric hospital. She got along very well with her roommate, but when the roommate was discharged, she had another breakdown and again lost her mind.

Due to the unpredictable nature of Alexandra's condition, it has always been difficult to behave appropriately, as I lack the necessary training, despite reading a lot about this illness - both my husband and I have a scientific background. I have a calm, balanced temperament and have avoided conflicts all my life, but Alexandra's illness has shown me that I am lacking something, that I might not always find the best words or attitudes.

However, at my age, I can no longer support Alexandra mentally. She is socially withdrawn, has no friends, and didn't start a family. I believe that patients who have elderly caregivers and no other social contacts face permanent existential stress, fearing the imminent loss of those caregivers, institutionalization and the total loss of freedom





52 George - a brother caring for his sister

George is the 45-year-old brother of his 34-year-old sister Anca who was diagnosed with paranoid schizophrenia 4 years ago. George recounts that Anca has no insight into the illness anymore and refuses medication. He describes a dangerous situation when Anca was in a psychotic episode. Also, George reflects at length about the lessons he has learned over the past years in the role of a brother who tries to help his sister. (72 words)

“It is essential to maintain a committed attitude and combat feelings of helplessness or abandonment”

I am a trained radiologist and Anca is a medical doctor as well (who worked for a pharmaceutical company before she became diagnosed with schizophrenia a few years ago). The biggest issue with Anca is her current refusal to accept the diagnosis and the treatment. This makes the situation even more tragic because Anca has originally responded very well to treatment with a simple medication regime.

Caring for Anca has made me experience difficult moments involving emotional exhaustion, physical demands, and financial expenses, as I often had to interrupt my work to be able to help her. Some of these moments coincided with the COVID pandemic when traveling was more difficult. There were times when several issues occurred simultaneously affecting both Anca's health and our parents' health.

A particularly overwhelming situation occurred a year ago when Anca, as I later learned, was haunted by threatening voices and felt persecuted by the mafia. She fled the city and travelled for help to an old friend whom she had once trusted. She was in a decompensated state and ended up confused at a train station at midnight with no way to get back home.

I could not personally go there, since I was on duty in my hospital, and had to find a friend who could go at midnight to bring her back. Initially, I was overwhelmed with a mix of anxiety, worried about her situation, not knowing if she was safe; frustrated that I couldn't personally go; but also angry that she had ignored all advice and ended up in a dangerous situation. Until I received confirmation that she had been safely recovered, I hoped nothing bad had happened to her, knowing that in such states she could get involved with strangers without realizing the risks.

After the incident, we discussed the severity of the situation, the risks involved, and the negative consequences. I noticed that such incidents became less frequent, although other risky habits remain.





Our interaction requires constant adaptation to new situations, finding solutions, and learning. I have tried to educate myself as much as possible about her illness, find inspiration from similar cases.

Over the years I have learned that I cannot control everything in relation to Anca. It is important to quickly overcome the initial shock in a critical situation and focus my energy as soon as possible on finding solutions. Additionally, I have realized that blaming and reproaching are counterproductive in resolving critical situations; they only serve as a release valve for reducing anxiety and nervousness.

Accepting that zero risk does not exist in life is essential. I created a broad support circle with people helping in different and complementary ways. I aimed to build a relationship based on trust, but her paranoid ideas make this difficult. The results are mixed and vary over time, I generally find it easier to expand the circle of support than to gain trust or ensure long-term compliance.

I have learned not to be surprised by anything and that I can be wrong in my predictions regarding Anca's life. To make a metaphor, life for a person with such a condition without treatment is like navigating the sea, alternating between stormy periods with high waves and calm periods without waves. We must enjoy the calm periods and draw energy from those moments. Over time, the intensity of the storms tends to decrease, the positive phenomena may diminish, but the negative ones can become more complicated.

It is essential to maintain a committed attitude and combat feelings of helplessness or abandonment. We will not always succeed, and we cannot eliminate all risks, but if we manage to improve the situation even by a small percentage, it is a great help and important for those in need. Patience, compassion, and understanding are crucial, though it is difficult to provide them in infinite quantities, but we can try as much as we can.

At the same time, we need to have a life of our own outside of these problems to maintain our own health. It is necessary to find interests and activities outside of the illness that help all of us involved, both the affected and the supportive ones. It is essential to avoid our interactions being solely about the illness and the worries associated with it and to create happy and relaxing moments.

Despite the challenges, I remain optimistic. I continue to make plans for future joint activities, to find realistic and practical solutions depending on the situation. Maintaining an open attitude, adapting to the situation, accepting uncertainty, and continuous learning are key. I also hope for progress in medicine, based on new biomolecular techniques, to identify specific mechanisms of the disease and discover new effective treatments.



53 Rozalia - a mother caring for her daughter

Rozalia is the 77-year-old mother of Dalia, now 49 years old, who was diagnosed with schizoaffective disorder (manic type) 30 years ago at the age of 19. Rozalia describes how psychotic episodes of her daughter required frequent hospitalisations, but also how Dalia was able to keep jobs for extended periods of time while she was taking medication. (57 words)

“Her former boss once wrote her an email, saying that a diagnosis is just a string of words that do not define you as a human being”

Our story begins in a summer more than thirty years ago, when my daughter Dalia, was just 16 years old. One day, after a rather agitated period, she told us she had been bitten by a horse. Indeed, she had quite a large bruise on her arm, but we, her parents, found it difficult to believe her, without knowing exactly why.

Truth be told, her behaviour had recently changed: she had been more outgoing than usual, extremely talkative, excessively cheerful, somewhat cheeky, and so on. She wouldn't sleep at night, but didn't feel tired; on the contrary, she had more energy than ever—“euphoric” is the right word.

I got worried because of the bruise on her arm and the story with the horse and decided to take her to the Infectious Diseases Hospital for a rabies vaccine. From there, we were referred just down the street to Child Psychiatry, where she was admitted for a month. The diagnosis was “bipolar affective disorder, manic episode without psychotic features.” You can imagine how devastated we were! We didn't know what to do...

The following years were relatively calm until she finished high school and had her first hospitalization as an adult in the closed ward of a psychiatric hospital. It was more severe than the first time. She had told us that she belonged to a group of famous fashion designers in Paris, was in telepathic contact with them and received secret messages from them through the street names of our city.

This hospitalization lasted two months. At discharge, she was diagnosed with “schizoaffective disorder, manic type”. Her doctor explained to us that any significant life changes might destabilize her condition and that it was a chronic illness. A difficult “verdict” at just 19 years



old, when life is just beginning! The doctors also said that taking medication continuously would be essential.

Fortunately, Dalia was a “model” patient (as her doctor used to say), especially because she never wanted to reduce her medication dose, even when she felt well — something rarely encountered in such patients, as I was told. However, while Dalia over the last three decades had some good periods and was working in several jobs, many relapses occurred.

At first, Dalia attended a 3-year Advertising College and then got a job entirely on her own at the main theatre of our city! She worked in the Props Department and absolutely loved it. Unfortunately, as all good things end quickly, she ended up in hospital again. Sadly, she could not continue at the theatre because someone else had taken her position by the time she was discharged from hospital.

After some time, she completed a photography course and got a job at a photo studio. Later, her last job was as a sales representative for a French cosmetics company. Altogether, she worked almost 10 years, during which she also had numerous hospitalizations. At one point, she managed to avoid hospitalization for five years because she had learned to identify symptoms early and self-manage her medication.

Ten years ago, her doctors suggested that she retire due to her illness. We have always lived together, and Dalia can organize her time as she pleases, which matters immensely! Last year, when she lost her father, she struggled greatly with this blow of fate and was hospitalized again. But with God's help and medical care, she recovered.

Dalia was sometimes asked if there were similar cases in the family—a question she couldn't initially answer. Until one day, her father (may he rest in peace...) opened up and told her about his sister and mother, who had similar mental health issues. Knowing this calmed her a bit from that perspective, if we can say so.

Her former boss once wrote her an email, saying that a diagnosis is just a string of words that do not define you as a human being. This is a lesson that anyone who has ever met a person with a "special life situation" should learn...





54 Adriana - a mother caring for her daughter

Adriana is the 59-year-old mother of 30-year-old Rodica, who was diagnosed with paranoid schizophrenia two months ago but who, in hindsight, had shown symptoms of schizophrenia already much earlier. Adriana tells how she had misinterpreted Rodica's strange behaviour for a long time before thinking of seeking professional help, and how a violent incident involving the police finally led to Rodica's psychiatric hospitalisation, diagnosis and treatment. (65 words)

"I've learned that we should have sought specialized medical help much earlier"

In hindsight, it all had started about two years ago when Rodica was working as a shop assistant in a bakery - but we didn't realize at the time that it would develop into a mental disorder. One day she came home from work earlier than usual. She said that she was under a lot of stress at her job because of a shortage of staff, that she couldn't bear the situation anymore, that she had been suffering from headaches and heart palpitations for a few days and that she felt sick. In passing, she said that on her way home someone had been following her. She was agitated, anxious, and nervous and we attributed everything to her stress at work. Shortly afterwards, she quit her job.

In the days and weeks that followed, she was still anxious, didn't leave the house, withdrew from us parents, stayed most of the time in her room, seemed to be solving puzzles and reading books. We didn't interfere, thinking she needed time to recover from her condition. In fact, after two months she seemed to recover. She started going to the gym and slowly tried to return to her daily life, though still fearful.

My husband and I stood by her, encouraging her to socialize, reassuring her that she could do it. I didn't realize that it could be a major problem. I thought it was something temporary, caused by that work stress and other frustrations I knew about. I believed that time would resolve everything. I thought that with rest, peace, and being surrounded by affection, she would recover. For two years, she engaged in various activities on her own but never tried to find a new job. Slowly my husband and I started to worry.

A shocking situation arose when Rodica suddenly said that she knew now that my husband and I were not her real parents. In a moment of honesty, she told us that she stayed in paranormal contact with her real mother, who for various reasons couldn't come out with the truth in public.

Rodica also said that she could read other people's thoughts and wanted to learn how to implant thoughts into other people's brains, just as other people were implanting thoughts into





her brain. She stopped sleeping, eating, and washing herself, wore the same clothes all the time, and hoarded items, fearing they might disappear (even things like packaging). We continued caring for her while she stayed in her room.

I was physically and mentally devastated, unable to believe that I was living through such moments. I tried to take her to the doctor, but she refused, saying she wasn't sick. I fought for several months to convince her to see a doctor. We went through difficult, even horrific times, when, for instance, she accused me that already a couple of years ago I had conspired with the boss of the bakery, to put her under stress. My husband and I were completely helpless.

When Rodica started throwing bottles out of the window one night two months ago, the police came, and she was involuntarily admitted to a closed ward of a psychiatric hospital where she still is today. Doctors say that she suffers from paranoid schizophrenia. Rodica receives medication and has distanced herself from her strange ideas, accepts that we visit her and talk to her. This gives me some hope that with specialized medical help the outcome will be good.

I now know that we should have sought specialist medical help much earlier. In retrospect, I am inclined to say that it was perhaps not only my lack of knowledge about mental illness but also my fear of stigmatisation by our family and the neighbours that it took so long before I thought of looking for professional help.





55 Liviu - a father caring for his son

Liviu is the 72-year-old father of his 41-year-old son Dan, who was diagnosed with schizophrenia 17 years ago at the age of 24. Liviu describes how the family spent a lot of time with Dan outdoors to keep him going, with the final breakthrough achieved by the involvement of a voluntary psychosocial association where Dan receives the appropriate support and is in a stable condition. (65 words)

“It is crucial to stick to the treatment and have as much patience as possible with the person diagnosed with schizophrenia”

Let me start by presenting the situation in our family. We are a family of seven—four sons, one daughter, and the parents. Dan, our problematic son, is the second child. He was never very communicative, but we just thought that was how he was, and didn't worry, because he was just one of five children, and they got on well with each other.

The problems started late, after he had finished high school and tried to take his college admission exams. It was a very stressful experience for him, and he didn't succeed, so he joined the army. There, his health deteriorated, and when he returned from the army, he was completely different.

He didn't talk much, and his way of thinking had changed, as if it was blocked, and he often said confused things. After a few months, we took him to our general practitioner and he referred us to a psychiatrist, where his illness—paranoid schizophrenia—was diagnosed.

As parents, we struggled to adjust to the situation. We knew nothing about the illness. Dan had isolated himself completely from everyone, including his siblings, and communicated only when absolutely necessary. He was prescribed a lot of medication and slept a lot, even during the day. That marked the beginning of a very challenging time with Dan. He needed constant supervision, like a child. His thoughts and behaviours were different. He didn't listen to us, got angry quickly, and forgot things.

It was very difficult for us to manage the situation. We used to take him out for walks because he had withdrawn into himself and wouldn't communicate with anyone. Two or three years passed like this, and then we had a very challenging experience with him. He had not taken his medication for a week, which led to extreme nervousness. And one day Dan became agitated, screamed, and wanted to destroy everything in the house. We were very scared—we had never experienced anything like that before. We barely managed to call the ambulance to take him to the hospital.





After that hospitalization, he was given more medication. Eventually, he began taking his medication on his own and got used to his situation. At some point, we learned about the activities of a voluntary psychosocial association which was a turning point for Dan and for us. Now he has a place to go where he can communicate with others facing the same challenges. Most importantly, he receives support from the association, and we are very satisfied with the help they provide.

In the meantime a better medication was found for Dan. He adheres to it, and his situation has improved significantly. You can communicate with him now. He even goes shopping on his own. Sometimes he forgets things, so he writes them down on paper, but it's a big improvement.

Since I am retired, I can now dedicate most of my time to caring for Dan. What I would say to other parents is that it's crucial to stick to the treatment and to have as much patience as possible with your sick family member. In the end, things will get better. I'd like to thank everyone at the psychosocial voluntary association and everyone else who provides assistance and help to those in need, working together with us to keep things under control.





56 Ani - a mother caring for her daughter

Ani is the 62-year-old mother of her daughter Babi, actually 35 years old, who was diagnosed with schizophrenia 13 years ago at the age of 22. Ani describes in detail how Babi's delusions of persecution which included her family led to a dangerous situation, but how later on, with the help of medication and the support by a voluntary psychosocial association Babi's situation has stabilised but still requires intensive help from her family. (73 words)

“My daughter has lost her independence and her desire to be active”

The illness has completely changed my daughter Babi. From being an ambitious young woman — a second-year social work student with purpose in life and an interest in broadening her knowledge in various fields—she has become detached from reality, dominated by hallucinations and false beliefs. During the onset of her illness and her first severe decompensation, she engaged in reckless behaviour that put her physical safety at risk. And this was especially difficult for us.

Early on, when Babi had already been diagnosed with schizophrenia but was stable, she asked me one Sunday morning to come with me to the church where I am used to sing in the choir. While I was singing near the organ, she ran out of the church. When I noticed she was gone, I went to the police, explained her illness and diagnosis of schizophrenia, and asked for their help in finding her.

I never imagined something like this could happen. I was terrified we wouldn't find her. Our family members were also overwhelmed. Besides the police, my husband and her grandparents went out searching for her in the streets, fearing that she might be in danger, especially if she were approached by a stranger in her vulnerable state. Fortunately, a police officer thought she might have gone to a friend's house, and with this suggestion, we managed to find her and bring her home.

The following day, she was admitted to the psychiatric hospital. There, doctors tried various combinations of antipsychotic medication until they found the right treatment for her. Although electroconvulsive therapy was repeated several times, it had no effect.

A few months later she told me that on that day the voices had told her that we, her parents, wanted to kill her, and that if she wanted to survive, she had to hide from us. The voices had instructed her to come to church with me because they knew I wouldn't be able to watch her while I was singing in the choir, allowing her to escape.





In the years that followed she regained some independence, with the right medication that reduced her symptoms. She went to her psychiatrist for checkups and prescriptions on her own and participated in activities organized by a voluntary psychosocial association attending various courses. She also went to concerts, theatre and opera performances and sang with me in the church choir. She showed concern for elderly family members, whom she visited alone. The following three years were likely the best for her and our family.

Unfortunately, relapses followed and she underwent multiple hospitalizations over the following years. As parents, we endured many periods of disappointment, which we had to learn to cope with. We stayed by her side during her long hospitalizations and spent a lot of time with her.

Although my daughter has been on medication for years, to which she responds well, she still requires a lot of support from the family. This is because she has lost her independence and her desire to be active. I am now retired, which gives me more time to care for my daughter. Currently, we try to involve her in various activities, both at home and at the voluntary psychosocial association.

Looking back, I must say that after our first contact with psychiatrists we, as caregivers, were given very little information or support on how to help her. As parents, it was very difficult for us to understand what was happening to her. To better understand her illness, I started reading about schizophrenia, also on the internet.

I also had the chance to read stories from other caregivers. This helped me understand that every family goes through similar, painful experiences. It also helped me understand her illness and become more confident that her medication would eventually improve her condition.

The psychological suffering of the family lies in their inability to help the patient and in witnessing their cognitive decline and personality changes. It is said that schizophrenia is like any other chronic illness, but it changes the destinies of both the patient and their family. It is essential for families to seek help from a specialized service as soon as they notice cognitive or behavioural changes in a family member, putting aside the stigma still associated with mental illness.





57 Sorin - a father caring for his son

Sorin is the 76-year-old father of his 47-year-old son Valentin, who was first diagnosed with obsessive-compulsive disorder at the age of 14 which was later changed to schizophrenia. Sorin describes aggressive incidents in the family which finally abated, when Valentin accepted depot injection which led to a more stable situation, but leaving Sorin still in fear what will happen when the family can no longer care for Valentin. (68 words)

“Looking to the future, our biggest worry is what Valentin will do when we are no longer here to care for him”

I am the main carer for my son Valentin. I am now retired, and together with my wife, I spend most of our time taking care of Valentin. We all live together in the same flat — Valentin, my wife, and me. He also has a younger brother who lives with his family in another town.

As a child, Valentin was diagnosed with obsessive-compulsive disorder, which later developed into schizophrenia. In the beginning, we had great difficulties with him. He refused to take antipsychotic medication, and he became violent and aggressive and had to be hospitalized.

At school, Valentin was withdrawn, sometimes having friends and sometimes not. He went to evening school, but he got into trouble often. Eventually, he managed to complete 11 years of education.

He got on well with a neighbour and visited him often. But when his illness broke out, they met less often and then stopped seeing each other altogether. Eventually, this friend moved abroad, and they rarely spoke, even on the phone or online. With his younger brother, Valentin was sometimes violent, and their relationship wasn't warm or fraternal.

At home, without us being aware, Valentin would sometimes put his medication into my tea and his brother's food. As a result, his brother couldn't attend two exams. So, we've been feeling very fortunate when Valentin got his medication in an injectable form.

Before that, he was causing considerable problems in the family. He was often agitated, verbally and physically aggressive. Once he barricaded himself in his room, which not only created trouble within the family but was also responsible for a scandal in the block of flats with the neighbours. We had to call the police and ambulance, and he was hospitalized.

His last hospitalization was three years ago. Since then, he has been receiving injectable treatment once a month and now every three months. Immediately after the injection the effect of the medication is evident - he is somewhat sedated and sleepy. As the three-month





period nears its end, he becomes slightly more agitated. We, as parents, are always anxious about him refusing the injection. Currently, with the antipsychotic injection every three months, he is stable, and we can live together.

Now that he's doing well and is more balanced, his mother is considering stopping his treatment. I keep insisting on how important it is for him to continue. The psychiatrist told us that stopping the treatment would be disastrous. He would decompensate severely, and there's no guarantee he could recover to his current state.

Valentin is under legal guardianship, so his pension and disability allowance go to us, his parents. However, we always give him money for his needs, especially cigarettes, soda, and coffee. Before we applied for guardianship, he spent a lot on various things, including alcohol.

In 2023, during the evaluation for guardianship, the commission was very unprofessional. The psychiatrist was inexperienced and suggested we take Valentin to another doctor for a different treatment, showing no understanding of our struggles and how difficult it was to find a solution for him.

Valentin sometimes helps me with gardening around the apartment building, like collecting leaves. He goes out alone to buy what he needs, mostly cigarettes and coffee. Otherwise, he spends most of his time in his room, on his phone or the internet, watching TV, listening to music, smoking heavily, and drinking coffee. It's good that he can stay by himself, as it allows us to take care of our own tasks.

Our younger son sometimes visits us. His daughter is very loved by us grandparents and by Valentin. However, his brother doesn't really let him hold his daughter because of the strong smell of tobacco. They communicate more frequently over the phone. Valentin enjoys talking to relatives, but they don't always have the patience for his stories.

Looking to the future, our biggest worry is what Valentin will do when we are no longer here to care for him. This thought troubles us deeply and leaves us in a constant state of unease. It makes us smile when he hugs us in the morning—it's a sign that he is doing well.





58 Bianca - a mother caring for her son

Bianca is the 74-year-old mother of her 49-year-old son Marius who was diagnosed with schizophrenia 15 years ago at the age of 34. Bianca blames herself and her husband – both were working as medical doctors – that out of fear of stigma they had tried to hide Marius' illness for a long time, and also reports how they have cared for Marius over all the years. With her husband having recently died Bianca had to decide to hospitalize her son permanently in a psychiatric hospital. (84 words)

“Both my husband and I were working, so we couldn’t adequately care for and supervise our son”

At the age of 34 my son Marius was diagnosed with paranoid schizophrenia, although the first signs had appeared much earlier. Due to our social status – my husband and I were both working as medical doctors – we had initially tried to hide the illness, for fear of being stigmatized by the family, relatives, and society.

The whole story began when Marius started drinking alcohol, soon every day and in increasing quantities. Because of this, he ate very little and poorly. He then began hoarding all sorts of trash (bottles, plastic containers, various unnecessary objects). He stored all this trash in his room in our apartment, which became very full and unhygienic. He would always lock himself in his room and wouldn’t let us in or clean it.

Over time, this also became a problem for the neighbours in the building, leading to numerous complaints, also to the police. He also neglected his personal hygiene and became verbally aggressive. He threatened family members, relatives, and neighbours. Again, we received numerous complaints from neighbours and members of the community, again involving the police.

Both my husband and I were working, so we couldn’t provide him with adequate care and supervision. He isolated himself from us, physically and emotionally. We tried every approach with him—talking to him about the issue, explaining things with good and bad examples, refusing to give him money, and no longer buying alcohol. We followed the advice of doctors and acquaintances in similar situations. And we attempted to stop his alcohol consumption.

When he became aggressive to neighbours, accusing them of threatening to murder him he was involuntarily hospitalized at a psychiatric hospital. We later learned that he had apparently hallucinated such threatening voices.





When he came home after a few weeks, we tried our best to supervise him to ensure he took his prescribed treatment, ate properly, and maintained his hygiene. The fact that he didn't accept his illness and refused to take the prescribed medication made him increasingly aggressive, nervous, and agitated.

For years, together with my husband and our other son, we tried to care for him within the family. However, it seems we couldn't control either him or his illness and he was very often involuntarily hospitalized over all these years.

I am now retired, and my husband passed away last year. I am living in an apartment building, and due to my own health issues and advanced age, I am no longer able to care for my son when he comes home from an acute hospitalization.

I am also the legal guardian of Marius and I have decided that he should remain hospitalized in a psychiatric hospital for permanent care for chronically ill patients. I visit him weekly and, together with his brother, allow him to come home on various occasions (birthdays, holidays, etc.) and to go out into the city.

Looking back, I now think that we should have accepted his need to be listened to and helped from the first signs. We should also have acknowledged his illness instead of hiding it. Perhaps more frequent hospitalizations or stricter insistence on continuing psychiatric medication treatment would have been needed.





59 Iulia - a mother caring for her daughter

Iulia is the 73-year-old mother of Lucia, who is 47 years old and was diagnosed with schizophrenia 25 years ago at the age of 22. Iulia has always cared for her daughter at home. She describes the ups and downs, the despair and the hope that she and her husband have experienced over the decades of Lucia's illness, and assures that she will continue to care for Lucia as long as she is able to do so. (77 words)

“As long as I am alive, I will take care of her, since, if she will be left alone, she will not be able to manage on her own”

My daughter, Lucia, has been a sensitive and reserved person since she was a child. However, when she started school, she adapted very well, studied quite well, and graduated from high school. After finishing high school, she couldn't get into college and didn't find a job right away.

This led her to lock herself up in the house and refuse to go anywhere. She cried a lot, said that everyone was laughing at her, and was very agitated. I took her to the doctor, who said she was only suffering from depression and that it would go away. This seemed to be true.

However, sometime later she locked herself up again inside the house. She was crying, and wouldn't open the door, screaming at us to leave her alone. We finally managed to take her to a psychiatric hospital. When we went to visit her, the staff told me that she didn't want to see me and her father. For three days, she felt very bad, wouldn't let me see her, and refused to see her father as well. That scared us very much. The doctor didn't give us much hope and said that she suffered from schizophrenia, and that he wasn't sure if she would recover.

From that moment on I couldn't sleep because I was so worried about Lucia, and I had severe headaches. Without realizing it, I suffered a heart attack. When I went to work, my colleagues noticed that I looked very pale and that my mouth was drooping. They told me I needed to go to the doctor immediately, but I didn't have the strength to go. My husband encouraged and supported me, telling me not to cry and that our daughter would get better again.

To our surprise Lucia got better and was discharged from hospital after six weeks. She was taking the medication prescribed by the doctors and felt well. And she managed to get a job in a bookstore. However, her employer noticed that she was taking medication and told her to stop, claiming it made her less attentive and unable to work.

Unfortunately, she listened to him, stopped her treatment, had a relapse and her employer terminated her employment contract. She was again hospitalized in psychiatry.





Stories of Care

Navigating mental illness together

We were all very scared—me, my husband, and her brother. We didn't know how to react or how to get through the situation. The psychiatrist advised us to find her something to do, some activity, so she wouldn't stay at home alone. When she came home from hospital our entire family encouraged her, telling her that things would get better. Unfortunately, she could no longer work as she quickly became physically and mentally exhausted.

Over time she was admitted to a psychiatric hospital several times and always returned to living with us.

These children are very isolated. The world condemns them for not wanting to do anything or work, but in reality, no one wants to help them or employ them. Lucia is fine now, but her condition can change very quickly. As long as I am alive, I will take care of her, since, if she will be left alone, she will not be able to manage on her own.





60 Victoria - a mother caring for her daughter

Victoria is the 72-year-old mother of her 48-year-old daughter Lidia, who had a troubled childhood and was diagnosed with schizophrenia 33 years ago at the age of 15. Victoria has cared for and supported her daughter all her life, putting up with her frequently aggressive behaviour. In recent years Lidia has calmed down and Victoria reports that they are now getting on well together. (64 words)

“I always made sure she had everything she needed, but she was never satisfied”

Lidia's illness began in her teenage years and has now lasted for more than thirty years. Already as a young child it was clear that something was wrong, as she was always very withdrawn.

I divorced her father when Lidia was only 3 years old. The reason for the divorce was his drinking and aggressiveness, which meant that I often had to run away from home when he became violent. I always thought her illness might have been caused by this.

At the age of 15 she started to withdraw into her room, staying in bed and talking to herself. I was able to talk to her when I brought her something to eat, but one day she told me she wouldn't eat it because it had been poisoned. After we had managed to go together with her to a psychiatrist, she was admitted to a psychiatric ward. There she was diagnosed with schizophrenia and started on medication. After a couple of weeks, she was discharged and returned home. Fortunately, she agreed to take medication, but stayed withdrawn and inactive most of the time.

I later got married a second time and have a second daughter from that marriage. My second husband was a very calm man which helped me to overcome many challenges with my daughter.

In recent years, there have been times when she didn't want to take her medication. Sometimes, she pretended to take it but would hide the pills in her mouth and then throw them away. During this time, she caused a lot of problems. She would throw various items out of the house, such as rugs, blankets, pillows, etc.

In addition, she would fill her bag with small items, leave, and then return an hour or two later without the items she had taken. I found dangerous objects in her room that could have led to a tragedy at any moment. Once, my entire left arm was bruised because she slammed a door on it when I tried to enter her room to give her medication.





She weighed 120 kg at that time (the doctors said it was a side effect of her medication, but medication was necessary). I was afraid of her when I saw her aggressive behaviour; I felt completely powerless.

Another stressing experience was that, if you didn't do something exactly the way she wanted, she would scream. There were three or four times when her screaming frightened me so much that for weeks all I could hear in my head were her screams until I felt completely drained.

I always made sure she had everything she needed, but she was never satisfied. At some point she was admitted to a long-term care psychiatric hospital but was later discharged. Since this long-term hospitalization, she has been taking her medication regularly.

We lived like this for many years until my husband passed away 10 years ago, and my youngest daughter got married several years ago. Since then, I have been living alone with her.

Fortunately, Lidia got better as she got older. Now, Lidia and I are getting on well. She loves to paint. When she has the patience, she also likes to crochet. She participates in various activities and groups of a voluntary psychosocial association, and I always encourage her to go.

