

## Living with a psychiatric disability: survival, life-art and lessons to be passed on

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I was not yet twenty when my first psychosis emerged. I was convinced that we were on the verge of a world war. The public defence sirens were tested every first Monday of the month. To me, those sirens meant that the cruise missiles had already been launched. We had just minutes to do what had to be done: find each other and wait to die. Sometimes I could actually feel the radiation taking effect. I felt nauseous and believed that my hair was falling out. The rest of the world pretended to carry on as normal, but I could see that everyone was afraid. They knew that we were all about to suffer a slow, painful death, but nobody knew how to prepare for it. And so we all continued our daily lives with stolid determination.

A psychosis is far-reaching and overwhelming. Many psychiatric complaints are far-reaching and overwhelming. They involve a severe distortion of your perceptions and senses. They render the world unfamiliar, unrecognizable, a threat. A psychiatric condition can turn life into a living hell. Just 'being' can no longer be taken for granted. Nothing can be taken for granted. Once you know that life will become unbearable beyond a certain boundary, once you know that you have such a boundary, very little can be taken for granted.

A psychiatric disorder is also accompanied by a sense of estrangement. What you *have* is often closely allied to who you *are*. The manifestations sometimes dominate your entire personality. The distinction between the individual and the condition is soon lost, and it is very difficult to regain.

One of the consequences of serious psychiatric suffering is that you will find yourself as a patient in residential psychiatric care. This too is an overwhelming experience for many, especially the first time. My admission to the psychiatric hospital damaged me in many ways. It may have been unintentional, but it damaged me nonetheless. When I think of the indignity that sometimes went with being a psychiatric patient, the self respect that I have since gained begins to waiver once more. When I recall the humiliation I sometimes had to bear, I become so angry that I forget that this is something in the past. No matter which way you look at it, psychiatric hospitals are repositories of human suffering. Added to your own misery is that which you see all around you. This, I believe, is one of the great contradictions of our mental

healthcare system: that we group together people who are experiencing so much distress and then expect them to start feeling better.

The longer you remain a psychiatric patient – becoming a ‘chronic’ patient in the jargon – the more likely you are to forget how to lead a normal life. Admission to a hospital means that you swap your familiar, trusted surroundings for the hospital life and routine. You can no longer call upon the person you were. Your main role in life becomes that of ‘patient’. But do not underestimate that role: it demands certain skills, such as the ability to adapt. As a patient, you have to fall into the rhythm and routine of the large hospital organization. You have to comply with the rules. Unfortunately, the dividing line between adaptability and submission is not always clear. And it can easily become less so over time. Once the sense of resignation has taken hold, you have absolutely nothing to help you regain your former position. A situation develops which could well endure until the end of your days.

The longer you remain a psychiatric patient, the more likely you are to forget the rules and structures of normal life. You forget that life is not always wonderful, and you forget that you used to be a person with both good traits and bad. As a patient, you learn to blame all the negative aspects on your condition. During my career as a patient, I learned to attribute every setback and every little disappointment to my condition. I now know that everyone has the occasional bad day when nothing seems to go right and the entire world seems to be conspiring against you. But for a long time, that sort of day would set alarm bells ringing for me because I thought that it was the precursor of a relapse. I had forgotten about life’s everyday irritations. I did not yet dare to take matters into my own hands, to lead my own life. I relied on the professionals: they were the experts. Other people knew how I should lead my life. I did not. When you are a psychiatric patient, it is extremely difficult to retain your self-esteem, values and opinions. And it is nigh impossible to explore or develop them.

We wrestle with our mental health and with the unpleasant side-effects of our care system. We also have to contend with the social consequences of our condition. We face prejudice and ever-decreasing tolerance in the community. That affects our social contacts, in the neighbourhood, in education and in finding work. There are regularly rants in the media denouncing our attempts to participate in society. Negative images are presented, based not on any facts but on emotions and the ‘rights’ of whoever can shout loudest. Those images present us as unpredictable, homicidal maniacs for whom the only answer is restraint and permanent confinement. There is no consideration for the social injustices, such as abuse and

violence, which turned our vulnerabilities into serious psychiatric suffering. We now have a government which has shifted the burden of the economic recession onto those people with least money and the poorest health. I could go on. It is certainly not only our own individual problems which we have to contend with. We must also establish a relationship with the causes and effects of those problems.

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I was not yet twenty when my first psychosis emerged. Twenty years have since passed. That first psychosis was not the last. I am still not rid of it. Am I expected to wait another twenty years until the cure descends upon me? Well, to be honest, I am not willing to do so. I have already decided that I will not wait for the doctor to give me a pill that will make me better. I have decided that my condition and I are two separate entities. I am *not* my disorder!

My life – and that of many other people with a psychiatric disability – is all about learning to cope with that which cannot be cured. We have not yet experienced the miracle of a cure. For many of us, waiting for one to come along is a complete waste of time. The psychiatric profession is not able to cure nearly as much as it likes to make out. Waiting for it to do so keeps us submissive and passive. It is better to ask, ‘what are the obstacles in my life, and how should I deal with them? In a marvellous article about self-determination and consumer empowerment<sup>1</sup> Van Hoorn, Bellemakers and Koster state that the question to be answered is: ‘what do you want to do with your life and what care and support do you need in order to cope with your disability?’ We are not psychiatric disorders with ‘care needs’: we are *people* with lives to be led, some aspects of which may require professional care or assistance. It is not important who provides such assistance or where. The prime aim is to enable us to lead our lives in the manner we wish. Care is a means to an end, not an end in itself.

To maintain an existence with a psychiatric disability is difficult enough. To build a life around that condition demands courage, perseverance and creativity. People with a psychiatric disability are true ‘life artists’. We tell each other about that life art in our stories, and in doing so we defend ourselves against the things that overwhelm us. Through our stories, we are able to see the difference between who we are and what our problems are. We learn to formulate our care requirements for ourselves. We

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<sup>1</sup> Hoorn, Ed. van et al: *De kleine zelfbeschikking en de herovering van de vraagsturing. Essay over alledaagse zelfbeschikking en de (on)mogelijkheden van vraagsturing*, [‘Small-scale self determination and the reconquering of consumer empowerment. Essay on everyday self-determination and the possibilities and impossibilities of the demand-led system’] IGPB, December 2003

devise stories in which we recognize ourselves. We search for the right words to do justice to these stories and we regain our own individuality. We can recount the stories and say, “that is my life, that is who I really am and this is how other people can help me.”

We help ourselves with our stories. We do a lot to help ourselves. We have a wealth of experience in doing so. We have learned how to assess the true value of our experiences and to put them together in a meaningful way. We try to learn from them what we all have in common and what sets us apart from each other. We attempt to identify what will help us and what will stand in our way. We develop knowledge: experience-based expertise. We pass that knowledge onto others, be they the next generation of care service users, the professionals, or people outside the mental health field altogether. Our voice can then be heard, our human face be seen.

The psychiatric survivors’ movement has a lot to offer. Perhaps more than we have realized thus far. We now see various new and creative initiatives which will strengthen our position and offer a different perspective of living with a psychiatric disorder. The main players include the Client Interests Bureau in Eindhoven, the ‘Wegwijswinkel’ in Utrecht and the GGZ Rijnmond User Council in Rotterdam. We develop training courses for professionals and for fellow users, and we start new self-help groups. Examples include a recovery course in Brabant, the Ziezo self-help organization, training of the Anoïksis spokesmen, and the national recovery programmes run by and for healthcare service users in Utrecht, Apeldoorn and Maastricht<sup>2</sup>. We present our own experiences in a form which will be useful to the professionals. Examples include the courses written by Conquest in Eindhoven and Amsterdam, the ‘Working with your own experience’ course produced by the GGZ Rijnmond User Council, and the ‘Clients training professionals’ project in Eindhoven. At national level, user organizations such as Weerklank and the Borderline Foundation have also started processes which will change the way in which psychiatric problems are approached, based on the experiences of the users themselves. Lastly, we are also working on our own research programme and are developing further expertise. Contributions have been made by the Versie Group, the Kwadraad Foundation and the Trimbos Institute. These initiatives, and the many others I have not been able to mention here, are presented today in order to share our vision, experience and knowledge with you.

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<sup>2</sup> See also: Boevink *et al.*, *Samen werken aan herstel. Van ervaringen delen naar kennis overdragen* [‘Working together on recovery. From sharing experiences to transferring knowledge’] Utrecht: Trimbos Institute, 2002.

User-run projects are gaining in popularity and in substance. In countless areas, we have initiated activities on the basis of our own 'helmsmanship'. The underlying motivation is the conviction that our experiences will lead to renewed insights regarding psychiatric disabilities and their symptoms, such as hearing voices or self-harm. We are also confident that we can contribute to a better type of psychiatric care services than those currently in place. Self-help and user-run initiatives are a response to the fact that our individuality, our experience and our knowledge are not yet adequately represented within mainstream mental health care services. For us, the emphasis is increasingly being placed on self-determination, personal responsibility and personal effort, rather than devoting our strength to railing against the power of others and their agenda.

To summarize, I believe that we have set in motion a development which will prove irreversible. We put forward our own experiences and are able to reflect upon them. We listen to the stories of other people with psychiatric disabilities and we integrate those stories into our collective arsenal of knowledge. We are coming to realize what themes and topics are of importance to us all, and we recognize the obstacles that face us. We are becoming aware of the history of the user movement. We are developing an understanding of the power relationships and the constrictive social structures. And against the dominant perspectives, we are demanding attention for the social aspects of individual psychiatric problems.

We are developing various initiatives by which our knowledge can be transferred to others. We train and advise users and professionals. We pass on the baton to those who follow us, supporting them in their development process. We are presenting examples of hope to those who consider their situation hopeless. In so doing, we open up choices to people who did not realize they had any choice at all. And we help to find the resources which can bring those choices to fruition. That is the strength of our collective. We pass on our knowledge, it provides a platform through which to pass on knowledge, we share a sense of unity, and we have solidarity in the difficult times.