

## Feeling Stuck?

### An Anonymous Note

Feeling “stuck” is common for people living with mental illness. One part of the syndrome probably involves a fair amount of grief for the sense of a lost self. There is also the real sense of dislocation that isolation and stigma can cause to those on medication or taking a break to deal with their illness. A diagnosis with schizophrenia or other mental illnesses such as schizoaffective disorder or bipolar disorder can be devastating to both individuals and families. It is a life-changing disruption. There is no going back post-diagnosis or pretending that it just didn't happen. I often think of it as the day I fell off the face of the earth into a fuzzy state of bewilderment and numbness. As a late intervention case, this also meant reflecting on many years of untreated symptoms and trying to make sense of the turbulence and damage. One person living with schizophrenia has already commented very candidly on the SFNSW website that one of the most troubling feelings is the inability to trust yourself again. What is inside your head betrayed you and rebuilding that trust with yourself can seem tantamount to putting your bare hands in a fire. For me, there is also grief for the loss of the drama of colourful delusions and moments of heightened awareness that seems to be flattened by medication. It must be difficult for anyone to imagine that you would miss the chaos and disorder but being removed from it feels still, eerie and strange. The psychotic episodes and the running at high speed from one thing to another; the exhilarating highs and crashing lows; the endless pondering about what is real and not real; and the chattering voices inside my head who stole so much valuable time from me. But these were part of the only psyche that I knew and my behaviour was structured around them. While the medications, CBT and voice therapy is helping, having to think about how to take control of your own life is a daunting new endeavour since it often means learning how to forge basic relationships all over again.

“Being stuck” means that you are often outside of society's networks of communication, support and employment where mental illness can rob you of those essential building-blocks of direction and motivation. Not only has trust been eroded, but so has the motivation to dwell further than the diagnosis. The inability to sustain goal-directed activities or just “having a go” at something is a common symptom often misinterpreted by others as laziness, ineptitude or complete lack of interest. Habitually abandoning goals in a state of fear is also blindly translated as recklessness or irresponsibility. Being in this temporal no-man's-land is like a form of mental and physical paralysis where the past and the future seem to have been obliterated from the consciousness and feelings of shame, guilt and emptiness replace the satisfaction of setting goals and achieving them. For many living with advanced or long-term illness, feeling “stuck” can feel permanent and there often appears to be no light at the end of the tunnel since the physical and emotional detachment is extreme. This seems especially poignant for those who live in isolated rural communities or who endure habitual bullying and abuse within their own homes and relationships. The November issue of *The Psychiatrist* in the UK reported that 60 per cent of women with mental illness have experienced physical violence from a current or previous partner.<sup>1</sup> This sobering statistic certainly puts the whole ordeal of being “stuck” for some in a completely different light. Hiding in the shadows therefore appears like a much safer option if your view of the world is filtered through the thick lens of ignorance and fear.

Treatment options for consumers in recent years have changed dramatically. The old idea that schizophrenia and other mental illnesses were permanent and degenerative disorders which followed a downhill and chronic course has generally been disproved by evidence-based studies which show that recovery or some form of improvement is possible. Empirical studies demonstrate that between one half and two thirds of people living with schizophrenia will show some or significant improvement.<sup>2</sup> Organisations such as the Schizophrenia Fellowship which are at the forefront of new approaches to mental health management offer comprehensive programs, support and advice in this area where holistic approaches to overall well-being are encouraged that go beyond the magic bullet of medication to encompass diet, exercise, spiritual well-being and other therapeutic options. But how do

you get onto this road if you're feeling completely overwhelmed with the day-to-day management of living with mental illness?

What is actually meant by the terms “rehabilitation” and “empowerment” is not always clear. They are also words that have lost any real meaning for those struggling with relapses, persistent symptoms or enduring prejudice. I guess the first stage is the hardest, and that is getting from being “stuck” to being “unstuck”. In a US-based study, Sharon Young and David Ensing found that initiating the recovery process is often the hardest struggle for consumers since it involves acknowledging and accepting mental illness which is often a threatening and painful realisation in itself.<sup>3</sup> Acceptance triggers the need to get help and to actively seek sources of treatment and support. Without accepting your own mental health condition and searching for sources of information, being “stuck” can become a permanent condition in itself. The process of acceptance also reignites a vital quality that we all need — whether living with mental illness or not — to motivate us to move from one day to the next. Without sounding too resonant of US election campaign slogans, being audacious and hopeful is both inspirational and transformative. Even when you're feeling completely hopeless and submerged in the dark waters of depression or delusion, believing that things might be different or that change is possible can have a powerful effect on your attitude. But how do you rebuild a sense of hope when the journey seems so long and where you feel so isolated and shut out of society? Of course, “hope” can't be quantified and it doesn't come in small bottles at the supermarket. It's a quality that can only be rebuilt through meaningful relationships with the outside world.

In an Australian-based study published in 2003 which involved 57 people who identified themselves as “in recovery”, participants identified 111 contributing factors.<sup>4</sup> 74 per cent of them saw the “determination to get better” as an important factor in their recovery and 64 per cent of them recognised that “finding their own way to manage their illness” was integral to their rehabilitation. 54 per cent of participants also said that “having friends who accepted them” was a factor that contributed to their recovery processes while 49 per cent thought that having spiritual beliefs was important.

Whether it be participation in organised religions or an inner sense of spiritual connection based on the principle of cohesion, the journey of spiritual awareness or enlightenment has a therapeutic effect. As Lieberman and Kopelowicz explain, almost all spiritual endeavours are underscored by the very same principles that motivate people to embrace change and think about self-improvement and learning processes.<sup>5</sup> One could add to this the importance of being attached to a supportive community. These different factors indicate that rebuilding self-esteem, trust and independence provide the foundations for these meaningful relationships and for finding a sense of hope. On the other end of the scale, 53 per cent of consumers reported that stigma continues to have a negative impact on their recovery. Hence, the battle against stigma and discriminatory attitudes can often be obstructive to the development of a hope, social connections and meaningful relationships.

The process of becoming “unstuck” through the recovery of hope can therefore be undermined by the continuing impact of stigma on people living with mental illness. And the quandary is finding a safe space where you can learn to trust again, rebuild self-esteem, feel part of a supportive community and start to develop deeper relationships again without battling adverse or discriminatory attitudes at the same time. If you are feeling “stuck” or on a recovery journey that has been thwarted by the continuing impact of stigma on your life, why not try volunteering in a mental health environment? In my own acceptance and recovery journey, volunteering has played a critical role. Alongside medications, cognitive work, spiritual awareness and other psychosocial forms of treatment and support, it is part of the therapeutic process. It has helped me face the diagnosis and accept it by learning more about it. It has given me a safe place in which to rebuild trust, develop co-operative bonds, and apply my skills for the benefit of something that comes back to benefit you.

This isn't always self-directed or about my own needs but about supporting others by seeing the bigger picture of the mental health community. From permanent staff you learn the art of listening, discernment and non-judgement. You learn from them that "empowerment" is about giving people the right to speak for themselves. You learn from carers about selfless and unconditional love and the value of just "being there". From other volunteers (some of whom have been donating their time for many years) you learn that to give something back is not a gift but a privilege. This isn't related to heroism or social martyrdom but to a sense of deep humility that one develops from reaching out to others. You learn from other consumers with more advanced illness so much about courage and fear where "rehabilitation" is often a life-long journey of self-discovery rather than a goal of "getting better". The exposure to all this rich life experience can't often be quantified but in another US-based study in 2001, Thoits and Hewitt concluded that volunteer work is beneficial to well-being independent of other forms of community participation.<sup>6</sup> It's a form of therapy in itself.

Far from wanting to paint a romantic picture of the therapeutic effects of volunteer work for mental illness management, it can also be confronting and challenging if you are on the "recovery" journey. Becoming "unstuck" is one thing, but remaining "unstuck" is another thing altogether. Learning to negotiate new boundaries again and finding the danger spots where "triggers" can cause a relapse or an exaggerated reaction can often feel like a dangerous place to be. Looking at yourself in a mirror can be harrowing and you might need to disengage every now and again to take the time to work out ways of developing resilience. Feeling your way through a minefield of unexpected emotions might seem short-sighted and dangerous but it allows you to learn to make informed decisions again and this can only be a beneficial thing for the development of insight. And in that process, you might find a quiet space with kindred spirits to rebuild that illusive thing called "hope". While it won't come in little bottles and the obstacles to get to it seem so big, it's out there waiting for you.

*This article was written by an SFNSW volunteer who is also a consumer at St Vincent's Hospital and is taking time out to find ways to manage his illness.*

**If you would like to learn more about volunteering at SFNSW, visit [www.sfnsw.org.au](http://www.sfnsw.org.au) and click on "Volunteer". For more information on recovery programs at SFNSW, contact Jill Steverson or Karen Karakaya on (02) 9879 2600.**

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<sup>1</sup> John F. Morgan, Gabriella Zolesa, Jane McNulty and Sharon Gebharat, "Domestic Violence among Female Psychiatric Patients", in *The Psychiatrist* 2010, 34, pp. 461-464.

<sup>2</sup> Courtenay M. Harding and James H. Zhaniser, "Empirical Correction of Seven Myths about Schizophrenia with Implication for Treatment", in *Acta Psychiatrica Scandinavica* 1994, 90/supp.384, p. 140.

<sup>3</sup> Sharon L. Young and David E. Ensing, "Exploring Recovery from the Perspective of People with Psychiatric Disabilities", in *Psychiatric Rehabilitation Journal* 1999, 22, 3, p. 222.

<sup>4</sup> Barbara Tooth, Vaidyanathan Kalyanasundaram,, Helen Glover and Sirous Momenzadah, "Factors Consumers Identify as Important to Recovery from Schizophrenia", in *Australian Psychiatry* 2003, 11 (supplement), p. 72.

<sup>5</sup> Robert Paul Liberman and Alex Kopelowicz, "Recovery from Schizophrenia: A Challenge for the 21<sup>st</sup> Century", in *International Review of Psychiatry* 2002, 14, p. 248.

<sup>6</sup> Peggy A. Thoits and Lyndi N. Hewitt, "Volunteer Work and Well-Being", in *Journal of Health and Social Behavior* 2001, 42(2), p. 126.