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Swimming with handcuffs on

ESSAY

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The parents of children with serious mental disorders carry much pain. How can they find the hope and strength they need to cope?

How does it feel to be the parent of a person over 18 who has a serious chronic mental disorder with a high severity of pain and extensive functional impairment? In this essay I will be trying to put into words the anguish that some of these parents have to endure. I will also attempt to identify sources of hope, and highlight the significance of hoping.

My background for writing about this topic is that my younger brother, three years my junior, was diagnosed with a serious mental disorder at the age of 17. He lived with this disorder for almost 50 years until his heart stopped beating in the late winter of 2016.

In the autumn of 2004, I was employed as the professional lead of a family liaison project controlled by service users. The project was set up by LPP (a national association for family members of people with mental health issues) in partnership with VfB (an association of adults working to support vulnerable children). The project involved a diverse group of family members, such as siblings, the adult children of a mentally ill parent, and the parents of children whose partners were unwell. Apart from providing a range of family liaison services, both associations are actively working to strengthen the position of family members in mental health services.

When words fail

Over the years I have seen and experienced how words can fail health professionals and family members alike when they seek to describe the situation that families find themselves in. One of the characteristics of the pain felt by families, is that to some extent, there is no language to describe it. It is certainly not a part of our casual day-to-day conversations. I have found that instead, many use metaphors and other figures of speech to express themselves. These figures of speech are not meant to be explained or analysed, but to be listened to with an open heart – our centre of intuition. A mother who was interviewed about a dramatic episode involving her son, who was seriously unwell, put it like this: 'It's been like swimming with handcuffs on'. To me, no other image used to describe the pain of families has ever felt as poignant. Personally, I have often thought about it as a form of torture, being so close to your loved one yet being incapable of easing their pain.

Chronically vigilant

I am not personally a mental health professional. In order to find the words to describe the pain of family members, I looked to Fjær and Skundberg-Kletthagen's summary (1). The authors point out that many mental disorders are characterised by fluctuating symptoms. Changes to warning signs and levels of functioning will impact family members severely. Should the person who is unwell try to take their own life and/or seriously self-harm, this can cause unbearable suffering among their loved ones. Even during good periods, family members will feel the need to be vigilant. Based on earlier experiences of deteriorating mental health, they will constantly be on the alert, prepared for disaster, and they can develop a gaze rooted in anxiety as they are on the lookout for small changes as a sign of a relapse.

When a family member is mentally ill, this is not about isolated incidents, but about experiencing repeated traumas, year after year. I have read the authors' description several times. While their text is compressed, it nevertheless describes situations that involve horrific pain for the person who is unwell as well as for their loved ones. Although I talk about 'the person who is unwell', I am acutely aware that this is someone who exists beyond their own mental disorder – yes, they are first and foremost a unique person with a personality, life story and wishes, dreams and hopes for their own life.

Secret closets

In their introduction, Fjær and Skundberg-Kletthagen write that from a social history perspective, mental health issues have been associated with prejudice and stigma. For the families, this has often made them hesitant about opening up about their own situation' (1). Stigma and prejudice give rise to shame, and shame is one of the most painful emotional conditions in human experience. They are hounded into secret closets where silence reigns, and suffering is never shared or processed.

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In this context I am particularly referring to how parents, especially mothers, used to be blamed, in superficial and shallow ways, for serious mental disorders (2). Or the person who is unwell has been seen as a symptom of harmful family dynamics, without this being based on any in-depth knowledge of the family. The necessary humility has been missing. Consequently, those who are blamed become rather defenceless. To me, this type of causation is the very heaviest burden that any parent can carry. Such explanations become an existential shock that may well sap the family of the energy they need to be their children's main supporters. Admittedly, attitudes have changed over the years in this respect, but parents still talk about being regarded with suspicion, often based on the narrowest of insights into the family's history (3). It is worth remembering that healthcare personnel will often be witnessing crisis behaviours: the way that people present when at the end of their tether. Or they may meet parents who are completely worn out.

Illustration: Weeping Woman (1883), Vincent van Gogh (1853 - 90). In public ownership, via Art Institute of Chicago

I have met relatives who felt that everything they used to believe about themselves as parents or family members was falling apart. They used to think that they were good enough parents and that their family history included many positives. I have been told several times that parents have moved their family albums out of sight, into the basement, or that they cannot bear to look through them. It is as if darkness increasingly pushes away the positives, thereby turning into a chronic, never-ending inner grief.

No wonder that parents isolate themselves. What they need, is to be met with a respectful, open gaze by healthcare professionals who recognise their own competence and adopt a non-judgemental attitude in their encounters with unique human beings, each with their unique family (4, p. 177).

Sharing the pain

I have heard parents talk about how they frequently wake up in the morning with a fear that their son or daughter has taken their life in the night. They have often refrained from sharing their worry with the other parent, for fear of making things worse for them. Explaining just how bad it is to a third party, feels unbearable.

Whether parents who wake up with this fear can share it with anybody else, makes a big difference. Family liaison work in mental healthcare is particularly important because it provides a setting where families need not feel disloyal to the person who is unwell. The professional involved is already familiar with the person's situation. They know the dramas that may have been unfolding for some time, the quashed hopes and the crushed dreams. Precisely because they know these matters from the inside out, in a way that no-one but other similarly affected families do, their actions are all-important. If the family is invited to put their pain into words, it may be possible for them to come out of the closet of shame and silence, because they meet people who they can share their own reality with.

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I see hope as the *wings of the soul*, a force for good that lifts people out of despondency and powerlessness and introduces new perspectives. What releases such forces is being listened to in a way that does not shy away from the seriousness of the pain, but validates it. It has been said that listening is an act of love. You no longer live in isolation with your anguish but are included in a community. Such inter-personal contact will always boost the spirit. You are not alone.

The foundation

The pain that families feel is not static. It is influenced by many factors, not least by the way they are met and cared for by therapists. I can hardly envisage any context that will allow therapists to make a greater difference for suffering people, and encounter greater gratitude, than when working with the families of those with the most severe mental disorders. Whatever you give to the family, you also give to the person who is unwell. This is not about providing perfect conditions for family liaison work. It is about courage, attitudes and behaviours – what we call interpersonal skills. This is a key aspect of the professional therapist role. Some will even refer to it as its very foundation (4, chap. 11).

Taking the time to comfort someone is particularly important when working with families. A compassionate personal presence that provides a hope that not everything will fall apart, can make family members feel less alone. The importance of this compassionate attitude cannot be exaggerated, and it can be as rewarding for the professional as for the family (4, chap. 1). Compassion is not about a superficial pat on the shoulder with a reassuring remark that 'everything will be okay'. On the contrary, it is all about making the person on the receiving end feel that the other person takes aboard their distress – that the pain is acknowledged and confirmed through both non-verbal signals and comments. Sympathy will not always be noticed, but compassion will. It is linked to what we refer to as 'active listening', which means that the listener not only hears what is being said, but also provides feedback that demonstrates empathy (4, pp. 246–7).

It is also immensely important that the listener is awake to the positive aspects of the family's interactions – the love and the loyalty – amidst all their suffering. For a family member, receiving such feedback is like gold dust and it can rekindle hope and courage beyond the realm of imagination.

Rights that give rise to hope

In their essay about patients' families as a source of knowledge, psychologist Kari Bøckmann and professor emerita Alice Kjellevold refer to comprehensive documentation that systematic involvement of families is hugely important (5). For the person who is unwell, such liaison can reduce the risk of a relapse, improve their level of social functioning, increase their chances of employment, improve their own adaptation to their disorder, and introduce a positive change to their emotional health. For the family, such involvement boosts their knowledge about the disorder and improves their coping mechanisms as well as reducing their sense of stress.

The importance of family liaison is highlighted in the comprehensive national guidelines for families published by the Norwegian Directorate of Health (6). Within the boundaries of professional, ethical and legal constraints, families must be included and recognised as far as possible in terms of information and liaison. It is equally important that family members receive support and care for their own part.

The painful gap

Sadly, there is often a gap between the statutory provisions set out in laws and regulations and the real-life family liaison provision. While this gap is recognised by Bøckmann and Kjellevold, it does not give the full picture (5).

> *«Sadly, there is often a gap between the statutory provisions set out in laws and regulations and the real-life family liaison provision»*

The gap represents a special form of pain experienced by families. Apart from being a breach of their rights, and a failure to provide what families rightfully expect and desperately need, the gap means that families are rejected when at their most vulnerable. There is an unexpected loss of trust. Families can find themselves in a situation which is so shocking and onerous that they themselves can become ill from what they have to deal with. At the same time, they need to provide support for the person who is unwell, and muster extra strength amid their own exhaustion and sense of helplessness.

I have often listened to accounts of hopelessness associated with this type of experience among families. My wish is that mental healthcare managers will be inspired by the national guidelines for families, and that they will use it as a compass. There is still a need to boost the rights of families and to give them a greater role to play in the treatment of the mentally ill. Based on my personal experience, I believe that families and healthcare professionals alike will find such a development in mental healthcare both meaningful and rewarding.

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