

# NSSS ADVOCACY BULLETIN

September 2017

## For Mental Health Awareness Week, Think Of The Caregivers

Marvin Ross's latest blog details the untenable situation that too many family caregivers for people with severe mental illnesses confront. <http://www.huffingtonpost.ca/author/marvin-ross/>

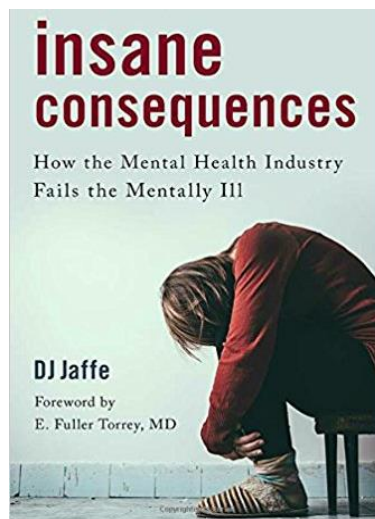
The first week of May, in Canada, is mental health awareness while in the U.S., the entire month of May is devoted to mental health. Then, in October, we have mental illness awareness in Canada and in the U.S.. I'm not sure why we have two but the one group that is left out of both are the families -- the long suffering heroes for many people with mental illness and, in particular, those with serious mental illness.

The other evening, I saw a commercial for UNICEF saying that no parent should watch their child suffer and they are right but the parents of those with serious mental illness do that every day while they struggle to help their adult children in an environment that often disdains families.

In his excellent book [\*Insane Consequences: How the Mental Health Industry Fails the Mentally Ill\*](#), author [DJ Jaffe](#) points out the insane consequences to the parents and families. He and his wife had taken in his young sister-in-law who was having problems.

When she spent hours one day screaming at the voices in her head, they took her to the emergency where she was admitted. She was diagnosed, medicated and provided with rehabilitative therapy and released.

But, in a commonly misguided attempt by the doctors to protect her privacy, Jaffe and his wife were not told anything even though she lived with them and depended upon them for support. She soon stopped taking her medications and was eventually re-hospitalized after she became catatonic. It was only then that they accidentally heard from a nurse that she had schizophrenia.



The European Federation of Families of People with Mental Illness ([EUFAMI](#)), a non-profit organization that advocates on behalf of family carers, conducted an [international survey](#) on the impact of serious mental illness on families.

The results are not pretty!

The survey of over 1000 people was conducted in 22 countries including Canada.

Four in ten respondents were dissatisfied with the support they received from doctors and one in three were dissatisfied with support from nurses. Only three in 10 were happy with the help they received from their social workers. Two thirds of people complained that they were not considered in important decisions being made for their family member and more than 60 per cent did not feel that the system professionals took them seriously.

EUFAMI points out that the shift away from hospital-based care makes the role of the caregiver essential in the support of their family members and yet they are often left out and ignored. Those who replied to the survey had been involved for over 15 years and were typically females aged 60. Three quarters of them are caring for a child and many feel depressed, lack proper sleep have feelings of anxiety and an inability to cope.

As Jaffe points out, "the moms and dads are the heroes, with siblings and children of the ill not far behind... but they are looked on as pariahs by the mental health industry." Doctors and others spout platitudes about the importance of family involvement until the family disagrees with their decision to deny their loved one care. "Then, all

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bets are off. The family doesn't understand or we have to empower the patient."

In March, I [wrote about a](#) Richmond Hill, Ontario mother who filed a complaint against her son's psychiatrist and I argued her case before the Health Professions Appeal and Review Board. One of the details was that the medication was ineffective and the family wanted what was being prescribed reviewed. The doctor refused to listen and told the family to leave his office while he discussed the prescription with his patient. He was found at fault by his regulator and ordered to write a 2,000 page paper and it is the lightness of that penalty that is being appealed. He refused to take into consideration the observations of the family who live with the patient and preferred his own observations based on four visits per year of 15 minutes duration.

An even sadder case that, by luck, was resolved without death, is that of [Judy Szeman](#). She had been discharged from a hospital only on the basis that she have a Community Treatment Order to ensure that she remained treated and taking her medication. These orders have to be reviewed regularly and at one review, her family was not told of the meeting. Ms Szeman's lawyer had the order removed since no family member was there.

She went off her medications and disappeared with no wallet, money, credit cards or cell phone. The Toronto Police held out little hope that she would be found alive while the Peel Regional Police conducted searches of ravines and rivers in the area of her family home. Two months later, she was found in a group home in Hamilton, ON.

At the core of this disdain showed to families is privacy legislation. Many jurisdictions have legislation that handcuffs professionals from talking to families about their ill relatives. Privacy is important but when it is the family and they are, as one author Jaffe quotes, "the new mental institution" providing shelter, case management, financial and moral support, they deserve to be consulted. Instead, many clinicians hide behind this privacy.

Privacy legislation aside, "Another reason why some clinicians are reluctant to share information with families is the lingering belief that families are a cause of the patient's illness." [That was written](#) in a recent journal article by Dr Richard O'Reilly and colleagues at Western University in London, Ontario. They suggest that the clinician ask their patient if they can include the family. Rarely, they say, is this ever done. The

clinician simply makes the assumption that the family is not to be included. If the clinician asks and explains the reasons why, most patients will agree.

"Some patients," they say, "may have specific information that they do not want disclosed, such as details of sexual behaviour. Most of these patients agree to family involvement when reassured that these details will not be shared. In some cases, clinicians might suggest meeting family in the patient's presence; this often allays a patient's fears. These steps are similar to an approach recommended in the United Kingdom and to recommendations made by the Mental Health Commission of Canada."

If consent is not forthcoming under any circumstances, the clinician can still listen to the concerns of the family in order to gain a greater understanding of what his/her patient is going through.

The bottom line is that outcomes for people with serious mental illness will be improved if clinicians bothered to listen and to include them. The stress faced by family caregivers would be significantly reduced as well. So, when thinking about mental health week/month or mental illness awareness, give some thought to the difficult and brave role that families play.

Give a family member a hug.