

## **Why is family involvement important?**

- Families are often instrumental in getting their ill relatives into treatment in the first place - contacting doctors, encouraging the ill relative to see a psychiatrist, taking them to hospital, fighting to get them committed if necessary (when, because of their psychosis and lack of insight, they resist treatment). By providing concerned family members and friends with background information and support, the North Shore Schizophrenia Society helps make this happen. Remember, too, that the earlier the diagnosis is made and the illness is treated, the better the "prognosis" (expected level of recovery).
- Information from family members and friends about the ill person's behaviour and symptoms ("collateral information") is crucial for the best possible assessment and diagnosis. After all, it is they who have watched the illness develop in that person and who know what he or she was like before they fell ill. NSSS advises those who are concerned with someone falling ill, or who is already psychotic, to keep a log of how the illness manifests itself, both to aid in diagnosis and to provide useful assessment information if involuntary committal is required.
- Families play a major role in post-discharge management - most importantly, through regular contact with their ill relatives where it occurs, providing monitoring and helping to keep them on their medication and, hence, avoid becoming psychotic again. Other interactions of patients with their families - social events, regular telephone contact or living at home, joint activities and support of all kinds - are major elements of rehabilitation. This post-discharge role complements the work of mental health teams (on the North Shore, Community Psychiatric Services), whose heavy caseloads often allow only periodic contact. In a best-practices model, where family and friends have a working relationship with the psychiatrist or mental health team, they can also provide ongoing monitoring and diagnostic information, including useful information about "negative symptoms," like sleep reversal and lethargy, and other manifestations like poor diet and hygiene.
- Family and friends can play a key role in alerting health care teams to any deterioration in those suffering from the illness, in calling urgent outreach when the situation becomes serious, and in getting those who become psychotic again back into hospital.
- If someone who again becomes psychotic falls through the cracks in the system, it is family members who most often act as the last line of defence, striving to get help for their ill relative.

Parents, siblings and/or friends, who have watched their loved one first deteriorate and then struggle with the illness, have the practical qualification of experience. They generally have an intimate knowledge of the progression of the illness, based on close observation. Through family-governed organizations like NSSS and, in best practices, through interaction with professionals, they also learn about schizophrenia and bipolar disease generally and how best

to respond when their relatives are not well (please see the relevant North Shore Schizophrenia Society programs and information resources detailed on this website, especially the Family to Family education course). They may attend support groups where experiences are shared. They read books and articles on the illness and attend public education meetings. They learn about impediments to treatment and blind spots in the system. If they have been involved with the ill person's difficulties over the whole span of time - usually the case - they may also have a substantial knowledge of the treatment history, including which medications were used in the past, what doses, what intervals (if the medication is given by injection), what worked and didn't work, the side-effects and effectiveness of different side-effect medications. This is an important diagnostic resource, especially when critical information from the past is either not passed on by treating professionals or overlooked.

Most important, family and/or friends come to recognize, through experience and repeated cycles, the small clues which indicate deterioration of the person's condition and the resurfacing of psychosis - signals not necessarily recognized by doctors and therapists with lesser contact and who may change over time; nor are these signals always immediately evident to outreach workers or the police when called upon to intervene. Families who are involved can work with the mental health team or doctor to see that these signs are addressed and can often, in this way, help to prevent major relapses.

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