The Schizophrenia Society of Ontario (SSO) is a non-profit charitable organization with a mandate to improve the lives of those affected by schizophrenia and psychosis through education, support programs, public policy & research. Reaching over 30,000 people each year, SSO is the largest organization representing people affected by schizophrenia in Ontario. Our organization has been an active advocate for access to treatment since our inception in 1979, which includes access to medications.

Schizophrenia is a serious but treatable brain disease affecting 1 in 100 people – approximately 120,000 Ontarians. Characterized by positive symptoms such as hallucinations and delusions, negative symptoms such as depression, and cognitive symptoms such as thought disorder, schizophrenia is a severe and chronic illness which at this time has no cure. Left untreated, the prognosis of schizophrenia is poor and can lead to deterioration of a person’s condition, decreased ability to function, and possible homelessness, suicide, violence and criminalization. The total cost of schizophrenia in Canada was estimated at $6.85 billion in 2004.

However, with treatment, the prognosis is much better and people with schizophrenia can lead meaningful, productive lives. It is therefore imperative that people with schizophrenia have access to the psychiatric treatment, community-based mental health services and social supports to aid them in their recovery.

As an organization representing the interests of people affected by schizophrenia, the SSO sees it as our role to help ensure that people living with this illness have access to the best and most appropriate treatment for them. In the area of drug therapy, we advocate that all medications deemed safe and effective by Health Canada for the treatment of schizophrenia be included in the Ontario Drug Benefit (ODB) Formulary. SSO does not endorse individual treatments of any kind nor do we make claims regarding the safety, efficacy or effectiveness of individual medications.

While we understand that there are financial constraints upon the Ontario Public Drug Program that limit its ability to reimburse medications, we believe that schizophrenia is a unique illness and that certain considerations should be made when making a decision about whether to list a particular medication:

1. **Medication is the cornerstone of recovery from schizophrenia**

   As mentioned, there is presently no cure for schizophrenia. Recovery is a term used widely in the mental health field to describe an individual’s ability to have a good quality of life with a mental illness. Recovery is supported by many non-medical factors, such as support, knowledge, and meaningful activity, however most individuals with psychiatric disorders indicate that medications are critical to their success. This position is echoed by the Canadian Psychiatric Association (CPA), which states in its Clinical Practice Guidelines for the Treatment of Schizophrenia that “pharmacotherapy with antipsychotic medications is an essential component of a treatment plan for most patients with schizophrenia.”

   Unlike several decades ago, individuals with serious mental illness no longer spend their lives in institutions. The process of deinstitutionalization has required that a network of services and
supports be provided in the community. While community-based mental health services and social supports such as income and housing are essential, for many individuals with serious mental illness the success of these interventions is linked to their psychiatric stability. Indeed, the CPA’s Clinical Practice Guidelines indicate that “psychosocial interventions work synergistically with medication to optimize treatment adherence and successful community living”.

For those who are hospitalized for a period of time, readmission at a later date is shown to be related to these same recovery factors, including access and adherence to prescribed medications. In fact, individuals with schizophrenia may be at significantly increased risk of hospitalization as early as ten days after going off their medications. This suggests that hospital admission rates, and related costs, could potentially be lowered with proper access to medication in the community, amongst other things.

The nature of schizophrenia is such that relapse is common, and the majority of individuals living with the illness will need longer-term treatment because relapse is associated with significant personal costs. This reinforces the need for access to medications throughout one’s lifespan.

2. **Because people with schizophrenia respond differently to different medications, they require a range of options**

The CPA is very clear in its Clinical Practice Guidelines for the Treatment of Schizophrenia that “medications must be individualized because the individual response is highly variable” and that “the choice of medication should be guided by individual patient factors”. This is an experience that has been echoed by many of the individuals and families that our organization works with. Many people living with the illness have told us that they have had to try several different medications before they found the one that was right one for them.

The need for individualized treatment is due partly to the fact that there is substantial individual variation in clinical response to the drug treatment of schizophrenia. In addition to this, one must consider the side effects associated with particular drugs and the impact those might have on the patient. Given the wide range of adverse effects and individual responses, treatment with antipsychotics needs to be tailored to the patient.

What our organization has found in speaking to people affected by schizophrenia is that when one does find the medication that is best suited to them, it can be devastating if that medication is not fully accessible to them through the Ontario Drug Benefit Formulary. Even fail-first requirements can have a negative impact on the patient, as they are required to take medications that may not be suitable for them before being allowed to access the one that might be best. Listing of medications on the Formulary can also affect physicians’ prescribing practices: a recent survey of Ontario psychiatrists showed that 50% of psychiatrists would not prescribe a medication that was not listed on the Formulary, even if, in their mind, it was the best treatment option for their patient.
3. **Individual responses to medications impact treatment adherence**

   Although antipsychotic medication has been shown to improve psychopathology, reduce relapse, and improve functioning, non-adherence to treatment is common. At a system level, non-adherence is associated with an increased use of Emergency Room visits and psychiatric hospitalizations, with one study finding that hospital expenditures of those who were non-adherent were more than three times higher than the hospital expenditures of those who were adherent\textsuperscript{12}.

   Medication side effects can significantly impact adherence to treatment along with the relationship with the clinician, patient and family knowledge about the illness, and understanding of the risks of non-adherence to medication\textsuperscript{13}. Indeed, we have heard from many individuals with schizophrenia that the side effects of their medications can be truly debilitating. This, again, reinforces the needs for options on the Formulary, so that physicians can freely prescribe medications which they believe will have the least side effects for that individual patient.

4. **People with schizophrenia are reliant on the Ontario Drug Benefit Formulary to access their medications.**

   Many Ontarians are fortunate enough that when they fall sick, they are able to get ready access to medications without significant financial strain. These individuals are often covered by employer-provided or personal health care coverage plans, or have illnesses which are temporary and require only short-term treatment.

   This is not the case for the majority of individuals living with schizophrenia. Schizophrenia is a chronic disease that often requires an individual to take medication for the course of their lives. Moreover, an estimated 80% of people with schizophrenia are unable to work for various reasons and rely on the Ontario Disability Support Program (ODSP) for income. Overall, approximately one-third of people receiving ODSP have a psychiatric disability, and 35,000 of those have psychosis-related diagnoses such as schizophrenia.

   Individuals with mental illness who are on ODSP can only access the medications that are listed on the Formulary. The significant disability associated with schizophrenia and subsequent reliance on the Formulary to access medications in a way that is financially sustainable should be a consideration when deciding whether to list a new medication. For these individuals, who live in poverty on ODSP, paying out-of-pocket for their medication is often impossible – even if it is the most appropriate medication for them.

For these reasons, in order to ensure optimal treatment, people with schizophrenia and their treating physicians must have access to all available treatment options through the Ontario Drug Benefit Formulary.
Sources:

4. Ibid.