



Position Statement

Provide Formal Support for Caregivers of People Living with Schizophrenia

Caregivers of people with schizophrenia shoulder an enormous part of the care their loved ones require, from providing emotional support to serving as treatment advocates to helping them understand and navigate their disease.

- Many provide full-time, unpaid care. An S&PAA survey of caregivers showed they spent an average of 40 hours/week on caregiving *in addition* to other responsibilities such as their own jobs.¹
- They spend thousands of dollars per month on everything from food and housing to medical care to legal services for their loved ones.¹
- They experience elevated physical, emotional and financial strain and social isolation.¹⁻⁶

Unlike other diseases that create disability, such as autism, most of these caregivers receive no in-home support services, no transportation services, no housing assistance, no formal training and little to no support from the healthcare system or governments. Much of the existing support for caregivers comes from mental health advocacy groups. The few resources available to these caregivers as they struggle to navigate their loved ones' care can be difficult to find, hard to understand, not detailed enough or all of the above. Government services (such as Social Security Disability and Medicaid) can have such stringent requirements that it can be impossible for their loved ones to qualify. As a result, caregivers by default often become full-time, unpaid health navigators, chauffeurs, cooks and social workers – a challenging role many are not equipped to play and should not have to.

To compound these challenges, schizophrenia is a complex disease to understand and treat. For example, the symptoms of schizophrenia can make people with the disease reluctant to sign HIPAA information releases, preventing healthcare providers from communicating fully with caregivers. One common symptom (called anosognosia) is the lack of ability to realize that you have the disease, often leading people with schizophrenia to refuse or discontinue treatment. This puts an enormous burden on caregivers and limits their ability to help. It can result in hospitalization, homelessness and incarceration – and debilitating stress for caregivers.

This discrimination against and neglect of caregivers has widespread negative impact on caregivers, those with schizophrenia and society.

Many caregivers cannot continue to work full time or at all. Some postpone or cancel education; others report being passed over for promotions.¹ This creates financial insecurity for individuals and families. And when formerly productive members of the workforce can no longer work, it results in lost productivity for communities and society writ large.¹

This is compounded by emotional stress caused by many factors, including the disabling and distressing symptoms of schizophrenia and the complex and confusing systems caregivers must navigate, from healthcare to insurance to housing to legal and criminal justice.

Many caregivers of people with schizophrenia also experience devastating isolation, forced to miss social and family events and unable (or reluctant) to take vacations. Many even avoid talking with friends or co-workers for fear of judgment and discrimination against themselves and their loved ones.⁷⁻⁹ Caregivers are at increased risk of multiple chronic diseases, due to stress-related conditions and because they may neglect their own personal health needs while caring for others. They also are at increased risk of experiencing violence from their loved ones with schizophrenia, which can result from inadequate treatment. In one study, at least 20% of caregivers reported experiencing violence in the past year.¹¹

Caregiver needs vary according to their relationship to their loved one.

In S&PAA's research, 28% of caregivers were parents of their loved one with schizophrenia, 18% were children, 16% were spouses or partners and 15% were other relatives.¹ Services should be adapted to address the unique challenges faced by each of these caregiver groups. For instance, parents of adult children with schizophrenia grapple with what may happen to their loved one once they die or can no longer care for them. Children of people with schizophrenia must navigate caregiving while also facing an increased risk of developing the disease themselves. Spouses often struggle with the emotional toll of managing the unpredictable nature of the disease while maintaining a romantic/intimate relationship. Tailored interventions are essential to meet these diverse needs.

The United States is taking unfair advantage of caregivers of people with schizophrenia, who play a critical role in supporting the more than 3.7 million people in this country who live with schizophrenia.

Without these caregivers, our country would experience an even worse epidemic of untreated (and undertreated) schizophrenia – and a resulting increase in homelessness, incarceration, loss of productivity and loss of life. Schizophrenia is already one of the World Health Organization's top 15 leading causes of disability worldwide,¹² and up to 20% of the homeless population is believed to have schizophrenia or a related disorder.¹³ We must recognize the important role these caregivers play and create programs and policies to support them.

Call to Action

S&PAA supports funding and policies at the relevant federal, state and/or local level to provide:

- Higher-quality integrated care for people with schizophrenia, as described in our [position statement](#) on that topic, to address the underlying cause of negative caregiver impact: the lack of effective comprehensive care.
- Case management services for all caregivers of people with schizophrenia, including intensive community-based treatments when appropriate, to ensure they do not have to navigate complex systems on their own. These services provide support in areas such as medication management, financial and legal frameworks and patient portal navigation.
- Creation and dissemination of easily accessible, digestible education options for caregivers that prepare them quickly and efficiently for caring for someone with schizophrenia. Educational assets should cover the full spectrum of caregiver responsibilities, such as:
 - What a good plan of care should look like.
 - How to secure disability status for a loved one.
 - Psychoeducation and skills training that helps caregivers support their loved one's recovery.
 - How to pursue housing.
 - How to set up legal support
 - How to follow and manage treatment.
 - How to best support a loved one when they are experiencing anosognosia or other persistent symptoms, and what to do when the disease is resistant to treatment.
 - How to identify and support a loved one's recovery path.

Healthcare providers, as the first point of care many caregivers encounter, should be aware of these resources so that they can direct caregivers to them as quickly as possible.

- Resources that provide medical and mental healthcare to target the physical and behavioral health consequences of caregiving for someone with schizophrenia, including both formal medical and peer-support services.
- Training for healthcare providers on anti-discriminatory, evidence-based and recovery-oriented practices. This should include:
 - Training on optimal and personalized medical and psychosocial interventions for people with schizophrenia.
 - Anti-discrimination education, as schizophrenia has been shown to be the most stigmatized illness by the very people who treat it.¹⁴
 - Training on the proper use of HIPAA to prevent providers from misinterpreting its rules, which can obstruct proper care by preventing families from both sharing and accessing relevant information.¹⁵

- More supportive community housing options to relieve family caregivers from housing and related financial burdens.
- Research that:
 - Documents the financial, emotional and social impacts of caregiving and the unmet needs of caregivers of those living with schizophrenia.
 - Supports the development of clinical interventions and policy changes to meet these needs.
- Respite and financial support programs to ease caregivers' physical and emotional stress and reimburse them for their unpaid roles as case managers, social workers and a variety of other "unofficial" roles.
- An improved, simplified government disability process for people with schizophrenia to prevent caregivers from having to shoulder expenses such as insurance, housing and treatment. People with schizophrenia often require public assistance such as Medicaid or Medicare, disability coverage and/or food subsidies. These programs require mountains of paperwork and are notoriously confusing – and many must be renewed annually.

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