

Independent market research companies Ipsos-Insight and All Global Ltd. conducted this international survey between November 2005 and June 2006 via 30-minute telephone interviews. The recruitment of respondents was conducted with the support of approximately 50 advocacy associations around the globe. Full listing is available at [www.wfmh.org](http://www.wfmh.org).

Caregivers in this study were most commonly the parent (31%) of the family member, followed by the child (24%), the spouse (17%), and the sibling (16%). They are very involved in their family member's treatment with 53% spending more than 10 hours per week caregiving.

## ABOUT WORLD FEDERATION FOR MENTAL HEALTH

The World Federation for Mental Health is an international interdisciplinary membership organization whose mission is to promote, among all people and nations, the highest possible level of mental health in its broadest biological, medical, educational, and social aspect. Consultative status at the United Nations provides WFMH a variety of opportunities to engage in mental health advocacy at the global level, working closely with the World Health Organization, UNESCO, the UN High Commissioner for Refugees, the UN Commission on Human Rights, the International Labor Organization and others.

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# Keeping Care Complete

*Caregivers' perspectives on  
mental illness and wellness*

## AN INTERNATIONAL SURVEY

*"Keeping Care Complete highlights the complete circle of care that is ideal for achieving long-term wellness for people, like my son, who are living with a serious mental illness."*

*- Sigrid Steffen, vice president of the European Federation of Associations of Families of People with Mental Illness*

*"Complete care is made up of effective medication, compassionate providers, robust community-based programs and empowered family members. As shown in the survey, family members can provide significant insight into these devastating but treatable illnesses."*

*- Carolyn Spiro, M.D., psychiatrist and sister of an individual living with serious mental illness*



World Federation for Mental Health

# Keeping Care Complete FREQUENTLY ASKED QUESTIONS

## What is Keeping Care Complete?

Keeping Care Complete is the first international survey to shed light on the important role of family caregivers of individuals with bipolar disorder, schizophrenia, and schizoaffective disorder.

Nine hundred eighty-two caregivers from **Australia, Canada, Germany, France, Italy, Spain, the United Kingdom, and the United States** participated in the survey, which was developed by the World Federation for Mental Health and Eli Lilly and Company.

Keeping Care Complete recognizes that mental illness affects not only the patient but also the loved ones who care for them. It also highlights the role that family caregivers play.

## What impact does relapse have on individuals with severe mental illness and their families?

**Relapse can devastate families.** Caregivers said that as a result of relapse their loved ones were unable to work (72%), were hospitalized (69%), tried to commit suicide (22%) or were imprisoned (20%).

For caregivers, a family member's relapse led to the worsening of their own physical and mental health (54%) and/or financial situation (26%).

## 63% OF CAREGIVERS

say they always or often worry about their family member experiencing a relapse.

Seventy percent of caregivers say their general well-being is greatly affected when their family member relapses.

## 76% OF CAREGIVERS

say doctors should focus on long-term care rather than managing crisis situations.

Sixty-six percent of caregivers said they were frustrated by a doctor's approach to set very low goals for long-term improvement of their relative's illness.

## What role does medication play in keeping family members well?

Ninety percent of caregivers say that an **effective medication is needed to control the symptoms** of their family members' conditions before their overall well-being can be properly addressed. Caregivers said that effective treatment has enabled their family members with severe mental illness to re-engage with family and friends (81%), perform daily tasks more independently (79%), stay out of the hospital (74%), learn a new skill/attend a class (48%) or hold a steady job/volunteer (42%).

## What other key factors did caregivers say are important in keeping their family members well?

Family members recognize the **importance of maintaining wellness**, defined as the condition of both good physical and mental health.

Many caregivers said that in addition to medication, the following factors are important in keeping their family members well: wellness programs (84%), family support (73%), social support (46%), talk therapy (34%) exercise (32%) and diet and nutrition (29%).

## Is stigma still a problem?

In addition to relapse, **stigma and discrimination toward those with a serious mental illness still exist** and 84% of caregivers said that these social factors make it harder for their family members to stay well.

## Where can caregivers go for help?

To access fact sheets with resources for caregivers and to learn more about the World Federation for Mental Health's efforts to support individuals living with mental illness, please visit [www.wfmh.org/caregiver](http://www.wfmh.org/caregiver).