

## **Keeping Care Complete Fact Sheet: International Findings**

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

### **Combined findings across countries**

The percentages below represent answers across all countries and a total number of respondents (982), unless noted otherwise. To view data sets from countries represented in the survey, as well as additional fact sheets on the caregiver perspective and serious mental illness, please visit [www.wfmh.org](http://www.wfmh.org).

### **Treatment Priorities**

Caregivers view effective medication as a top treatment priority:

- 91% of caregivers say that efficacy is their primary concern when considering treatment options for their family member.
- 90% of caregivers say that an effective medication is needed to control the symptoms of the family member's condition, before their overall well-being (physical and mental health) can be properly tackled.

Finding the right medication can be difficult and lengthy, and many people try different medications for years before they find the one that works.

Of the 756 caregivers who say that their relative is satisfied with their current medication:

- 56% say it took two years or more for their relative to find a medication that worked.
- 85% say that their relative tried more than two different medications before finding the one that worked and 36% say their relative had to try more than five medications.

In addition, 82% of all caregivers said that initial experiences with a treatment influence overall perceptions of the treatment.

### **Treatment Disruption and Relapse**

Treatment disruption due to change in medication and discontinuation are major causes of relapse, defined as the worsening of symptoms after apparent recovery.

Of the 502 caregivers who say their family member stopped taking their medication despite his/her doctor's advice:

- 91% of caregivers say that this led to relapse for their family member.
- 71% of caregivers say that as a result of medication discontinuation, their family members had to be hospitalized.
- 71% of caregivers strongly agree that their family life was disrupted as a result of their family member's discontinuation of medication.

Of the 455 caregivers who say their family member's medication was changed based on a decision made in cooperation with a doctor:

- 56% say that this change in their family member's medication led to relapse.
- 64% say that family life was disrupted as a result of their family member's medication being changed.
- 53% say that as a result of medication change, their family member seemed even less like their old self.
- 39% feel frustrated as a result of their family member's medication change.

### Consequences of Relapse

Relapse is a common subject of concern for caregivers and has devastating consequences for family members of people living with mental illnesses:

Of the 838 caregivers who said their family member experienced relapse:

- Caregivers say that as a result of relapse their loved ones were unable to work (72%), were hospitalized (69%), tried to commit suicide (22%) and were imprisoned (20%).
- 63% of caregivers say they always or often worry about their family member experiencing a relapse.
- Caregivers say that relapse disrupted their own lives substantially (61%), they became more fearful about their family member's condition and well-being (56%), their mental and physical health worsened (54%) and their financial situation worsened (26%).
- 70% of caregivers say their general well-being is greatly affected when their family member relapses.

### Impact of Successful Treatment

When effective, treatment for severe mental illness can lead to positive outcomes:

Of the 756 caregivers who say that their relative is satisfied with their current medication:

- Caregivers say that effective treatment 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%).

- 74% of caregivers say that successful treatment greatly or substantially contributes to their family member's overall quality of life.
- Family member's wellness and improvement of symptoms helped caregivers decrease stress levels (76%), decrease interpersonal tension (72%) and increase the amount of quality time spent with family (71%).

## Long-term Wellness

Caregivers want doctors to focus more on achieving long-term stability:

- 66% of caregivers say they were frustrated by a doctor's approach to set very low goals for long-term improvement of their relative's illness.
- 76% of caregivers say doctors should focus on long-term care rather than managing crisis situations.
- 98% of caregivers say that the goal of treatment should be to maintain wellness, defined as the condition of both good physical and mental health.

Individuals with severe mental illness benefit from wellness programs and family support:

- According to 73% of caregivers, family support is a key factor that keeps their family member well.
- 84% of caregivers agree that wellness programs are valuable in helping their family member manage their symptoms.

Stigma is still a barrier:

- 84% of caregivers say that stigma and discrimination make it harder for their family member to stay well.

## About the caregivers

- 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%).
- 75% are female.
- They are very involved in their family member's treatment:
  - 69% accompany their family member during visits with doctors;
  - 58% are the primary caregiver;
  - 56% weigh in on treatment decisions;
  - 30% administer the medication;
  - 53% spend more than 10 hours per week caregiving.

## About their family members

- 49% of caregivers said the diagnosis of their family members was schizophrenia, 45% answered bipolar disorder and 6% answered schizo-affective disorder.
- Most have been battling their illnesses for more than 6 years:
  - 48% say that their family member was diagnosed for more than 10 years.
  - 21% report the diagnosis has been in place for 6-10 years.
- 46% live with the surveyed caregiver and 30% live in their own apartment or house.
- 41% receive treatment at an outpatient mental health center, 33% receive treatment from an individual psychiatrist and 25% receive treatment from a primary care or family physician.

## Survey Methodology

Independent market research companies Ipsos-Insight and All Global Ltd. conducted the survey of 982 caregivers of individuals with bipolar disorder, schizophrenia or schizo-affective disorder or Australia, Canada, Germany, France, Italy, Spain, the United Kingdom and the United States between November 2005 and June 2006.

Data was collected via 30-minute telephone interviews, which included a set of close-ended questions focusing on topics such as treatment discontinuation, relapse, caregiver burden, information exchange between families and treatment teams and long-term wellness. In addition, the survey included several country-specific questions.

## Snapshot by country

### **Australia (N= 100)**

*Recruitment method:* Support groups, newspaper advertisement

*Participating support groups*

- ARAFMI, including Arafmi and NT Arafmi
- Mental Illness Fellowship of South Australia
- Mental Illness Fellowship of North Queensland
- Mental Illness Fellowship of Western Australia
- Mental Illness Fellowship of Northern Territory
- Mental Illness Fellowship of New South Wales
- Mental Illness Fellowship of Australia
- Schizophrenia Fellowship of NSW

### **Canada (N=199)**

*Recruitment method:* Ipsos online panel

### **Germany (N=100)**

*Recruitment method:* Support groups

*Participating support groups*

- LV Bayern ApK e.V.
- LV Hessen ApK e.V.
- LV Mecklenburg-Vorpommern ApK e.V.
- LV Rheinland- Pfalz ApK e.V.
- LV Sachsen ApK e.V.
- Angehörigengruppe Heidelberg
- Angehörigengruppe Offenburg Umland
- Angehörigengruppe Konstanz
- Landesverband Hamburg

### **France (N=100)**

*Recruitment method:* Support groups, newspaper advertisement

*Participating support groups*

- Club Loisir
- Pitha Kyesse
- Advocacy France
- SCHIZO? OUI!

### **Italy (N=100)**

*Recruitment method:* Support groups

*Participating support groups*

- Associazione Aiutamoli
- Fondazione Mario Lugli
- A.R.A.P.
- O.N.L.U.S.
- DI.A.PSI.GRA.
- Unasam
- Caffè Dell'Arte
- Progetto Itaca
- DI.A.PSI-Roma

### **Spain (N=83)**

*Recruitment method:* Support groups

Participating support groups were associations affiliated with FEAFES:

- FEAFES Andalucia
- AFESA Asturias FEAFES
- FEAFES Canarias

- ASCASAM Cantabria
- FEAFES Castilla-La-Mancha
- AFECEP Ceuta
- FEAFES Extremadura
- ARFES PRO SALUD MENTAL La Rioja
- FEMASAM Madrid
- FEAFES Murcia
- ANASAPS Navarra
- FEDEAFES
- FEAFES Comunidad Valenciana

### **United Kingdom (N=100)**

*Recruitment methods:* Support groups and online advertisement

#### *Participating support groups*

- MDF Bipolar
- Mental Health Network
- Rethink
- Mood Swings
- Making Space
- NSF (Scotland) (National Schizophrenia Fellowship)
- Hafal
- Mind

### **United States (N=200)**

*Recruitment method:* Ipsos online panel

Lilly and WFMH are grateful to everyone who contributed to this important survey. The commitment from leaders of country-specific support groups was especially critical to the success of the project.

### **About WFMH**

The WFMH 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.



## **About Eli Lilly and Company**

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