

Background for media

- In the past 50 years, a shift internationally toward community care and the de-institutionalisation of psychiatric patients has seen the transferral of much of the day-to-day care to family members.ⁱ In part, this shifting of responsibility has been caused by a deficit in community support services
- The profound psychosocial, physical and financial impact on the families of individuals with severe mental illness is comparable to other illnesses such as Alzheimer's disease, diabetes or cancer ^{ii, iii}
- *Keeping Care Complete* is the first international research to shed light on the experiences and insights of family carers caring for individuals with bipolar disorder, schizophrenia and schizoaffective disorder
- Carers from Australia, Canada, Germany, France, Italy, Spain, the United Kingdom and the United States participated in the survey, which was developed jointly by the World Federation for Mental Health, and Eli Lilly and Company
- 100 Australian carers were enrolled in the survey, with assistance from organisations including the Mental Illness Fellowship of Australia, Australian Relatives and Friends of People with Mental Illness and Carers Australia

Overall findings of *Keeping Care Complete*:

- The disruption of an individual's treatment for mental illness, and subsequent worsening of psychiatric symptoms can have harsh financial, physical and emotional consequences for that person's family
- Carers whose family members had relapsed said that as a result, their loved ones had experienced a range of devastating effects including an inability to work, hospitalisation, suicide attempts and imprisonment
- The effects of relapse extend to the carer, damaging their own mental and physical health, and result in substantial disruption to the rest of the family
- There is a desire among carers for doctors to focus on long-term care rather than managing crisis situations. Carers surveyed firmly believe that finding the right medication for their family member provides the foundation for stabilisation before an overall wellness plan can be contemplated

About the respondents:

In Australia, carers surveyed were most commonly the parent of the family member (63% vs 31% of the international sample), followed by: a child caring for a parent with mental illness (14% Australia, 24% international), a spouse (16% Australia, 17% international) and a sibling (5% Australia, 16% international).

Of the Australian carers, the primary diagnosis of their loved ones was: schizophrenia (63%), bipolar disorder (32%), or schizo-affective disorder (5%).

Key results:

The following percentages represent answers for Australian respondents, with responses from the total international sample (982) noted in brackets. Comparative graphs available on request.

Australian carers are highly involved in their family member's treatment:

- 65% (69%) accompany their family member during visits with doctors
- 80% (58%) are the primary carer
- 62% (56%) weigh in on treatment decisions
- 19% (30%) administer the medication
- 42% (39%) spend more than 20 hours per week caring for their relative
- 67% (51%) say that they and/or other family members participate in a support group

Relapse in a loved one has far-reaching impacts:

- 69% (61%) of Australian carers say they 'always' or 'often' worry about a relapse
- 48% (38%) say their loved one has experienced a relapse more than five times
- 96% (61%) say that relapse disrupts their own lives substantially; 90% (56%) said it makes them more fearful about their family member's condition and well-being; and 89% (54%) said it worsens their own mental and physical health
- Australian carers (at 86%) were more likely to report their loved one had been hospitalised as a result of relapse than the international total of 69%

Carers view effective medication as a top treatment priority:

- 92% (91%) of Australian carers say that efficacy (defined as symptom control and management) is their primary concern when considering treatment options for their relative
- 100% (98%) agree that the goal of treatment should be to maintain wellness (defined as both physical and mental health)
- 77% of Australian respondents say that an effective medication is needed to control the symptoms of the family member's condition, before their overall physical wellbeing and mental health can be addressed
- 85% (84%) agree that ineffective medication is disruptive to family life
- According to 97% of Australian carers, family support is the key factor, as well as medication, that keeps their loved one well. Of the international total, 73% agree
- Of the 502 carers who say their family member stopped taking their medication, 91% believe this led to relapse. 94% of Australian carers surveyed agree

Effective treatment provides positive outcomes for carers and their loved ones:

- 82% of Australian carers say effective treatment enables their family members with severe mental illness to re-engage with family and friends, and 88% said it helped them support their loved one to remain out of hospital
- 78% (74%) say that successful treatment greatly or substantially contributes to their family member's overall quality of life
- The key benefits of effective treatment (for the loved one) identified among Australians surveyed were: 88% - manage/improve symptoms (93%), 78% - attain a better quality of life (72%), and 69% - increase social contact (69%)
- When asked how a family member's improved wellness affected them, 88% of Australian carers said it decreased their own stress levels, 87% said it decreased interpersonal tension in the family, and 81% said it increased the amount of quality time spent as a family

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

- 70% of Australian carers (66%) say they are frustrated by their loved one's doctor setting very low goals for long-term improvement of the relative's illness
- 75% of Australian carers (76%) say doctors should focus more on long-term care rather than managing crisis situations

Stigma continues to influence treatment and causes discontinuation of medication:

- 88% of Australian carers (84%) agree that societal stigmas and discrimination against people with mental illness make it harder for their family member to be well
- 68% of Australian carers (63%) agreed that stigma against mental illness may have influenced their family member to discontinue medication

Methodology:

The survey was conducted by independent market research company Ipsos-Insight in co-operation with All Global Ltd. A total of 982 family carers of people with bipolar disorder, schizophrenia or schizo-affective disorder in Australia, Canada, Germany, France, Italy, Spain, the United Kingdom and the United States were interviewed 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, carer burden, information exchange between families and treatment teams and long-term wellness.

The *Keeping Care Complete* survey was developed jointly by the World Federation for Mental Health and Eli Lilly and Company. Further information on the global survey and fact sheets on mental illness are available at www.wfmh.com

For further information on the Australian component of the survey, please contact Lyndall Druery or Sarah Reed at Reed Weir Communications, ph: (02) 9436 2088.

i S. Stern, "Disruption and Reconstruction: Narrative Insights into the Experience of Family Members Caring for a Relative Diagnosed with Serious Mental Illness," *Family Process*, 38:353-369, 1999

ii G.D. Mays, "Male Carers of Mentally Ill Relatives," *Perspectives in Psychiatric Care*, Apr-Jun, 1999

iii M.S. McDonnell et al, "Burden in Schizophrenia Caregivers: Impact of Family Psychoeducation and Awareness of Patient Suicidality," *Family Process*, Vol. 42, No. 1, 2003