

Keeping Care Complete

Summary of key findings

In the past 50 years, an international shift toward community care and the de-institutionalisation of psychiatric patients has resulted in the transferral of the day-to-day care of people with mental illness to family members.¹ In part, this shifting of responsibility has been caused by a deficit in community support services.

The **Keeping Care Complete** survey is the first international research to shed light on the experiences and insights of people caring for individuals with bipolar disorder, schizophrenia and schizoaffective disorder. Nearly 1000 family 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. Findings identify many issues for Australian carers (100 were enrolled in the study) and allow comparison on numerous points with the other nations involved.

Respondents were asked about the influence effective treatment has on the overall quality of life for their loved one and its role in maintaining a stable family environment. The research shows that relapse has widespread impacts beyond the individual, placing great strain on those caring for people with mental illnesses like schizophrenia and bipolar disorder. It quantifies for the first time at an international level the common plight of family carers of people with mental illness.

Keeping Care Complete shows that carers view appropriate use of medication as the cornerstone for more holistic recovery from serious mental illness. The carers' perspective also confirms that, without community support and access to effective treatment, it is virtually impossible for people experiencing mental illness to reclaim their lives. The survey shows there are many gaps in the support services provided to Australian carers, who simply want to achieve the best possible quality of life for their family members.

Key findings of **Keeping Care Complete** are presented in this short report. Further details are available from www.wfmh.com or Eli Lilly Australia (Corporate Affairs), ph: 02 9325 4444.

¹ 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

"Keeping Care Complete is the first study of its scale and scope to assess the perspective of family caregivers and provide valuable insights into long-term wellness, treatment disruption and relapse, impact of successful treatment, and treatment priorities. Our hope is that, with increased awareness among legislators, medical professionals and the greater public, of the need for access to psychiatric services, medications and wellness programs, we will help alleviate the burden that these devastating mental illnesses can have on families."

PRESTON GARRISON

Secretary General and Chief Executive Officer
World Federation for Mental Health

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Keeping Care Complete summary of key findings

KEY FINDINGS

Overall, the **Keeping Care Complete** survey showed:

- > **The disruption of a family member's treatment for mental illness and subsequent worsening of psychiatric symptoms can have harsh financial, physical and emotional consequences for families**
- > **Carers whose family members relapsed said that, as a result, their loved ones 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 resulting in substantial disruption to the family unit**
- > **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**

SURVEY METHOD

Independent market researchers recruited 982 family carers of people diagnosed with schizophrenia, schizo-affective disorder or bipolar disorder. Australian respondents (x100) were recruited through local mental health and carer support groups between 15 November 2005 and 27 March 2006. Data was collected via 30-minute telephone interviews in the respondents' native language, 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.

About the carers

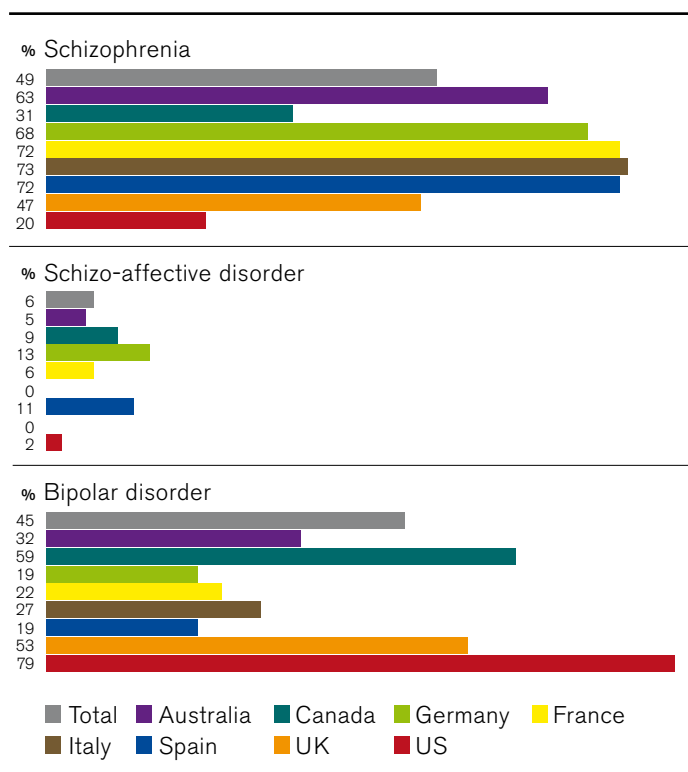
The following table shows characteristics of the Australian respondents versus the total international sample.

Characteristic	% Australian carers	% Total carers (all participating countries)
Carer is parent	63%	31%
Carer is child	14%	24%
Carer is spouse	16%	17%
Carer is sibling	5%	16%
Carer is other (niece, nephew, aunt etc)	2%	12%
Respondent is primary carer	80%	58%
Carer contributes to treatment decisions	62%	56%
Respondent spends more than 20 hours per week caring	42%	39%
Carer lives with the family member with mental illness	45%	46%
Carer is in daily contact with family member	56%	61%

Condition diagnosed

In Australia, the majority of respondents' family members have a diagnosis of schizophrenia. This chart shows the different diagnoses reported by carers in each country.

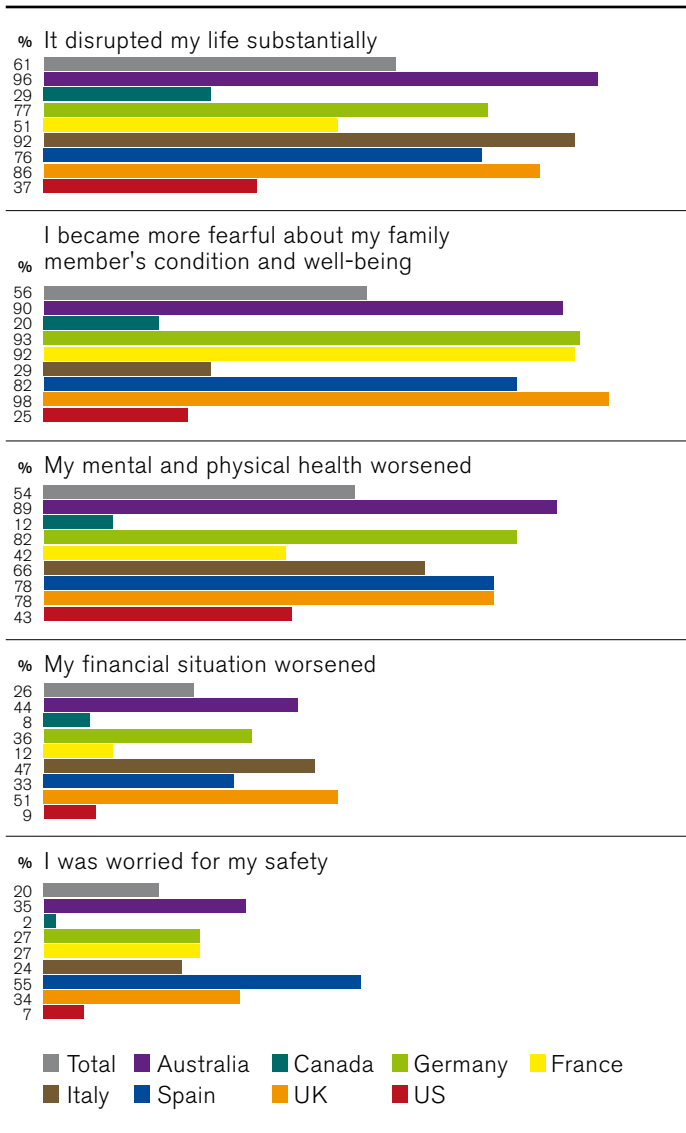
Q. Which of the following conditions has your family member been diagnosed with?



Effects of relapse on carers

Carers reported a loved one's relapse causes a variety of direct, wide-reaching and often devastating effects on the family, on top of generating concerns for their loved one's wellbeing, as this chart shows.

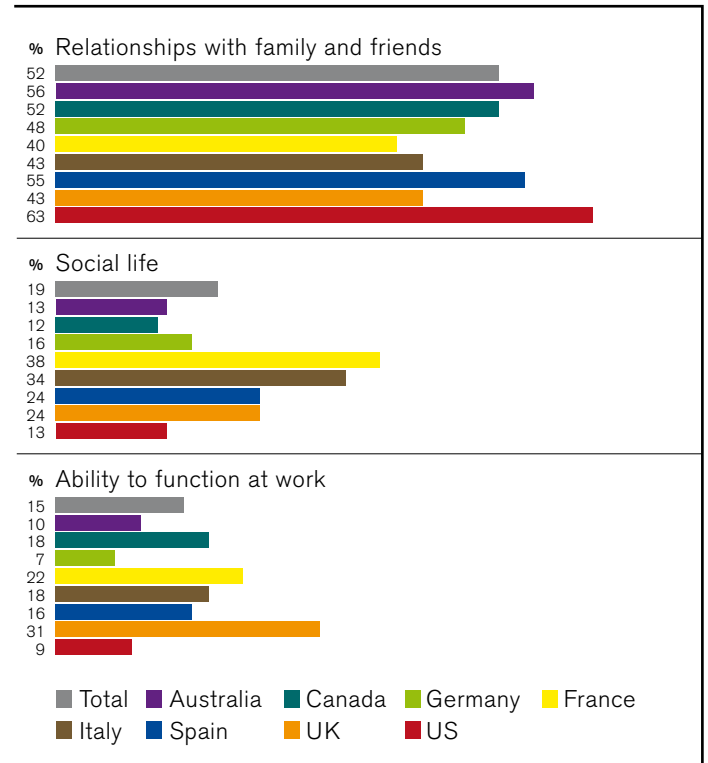
Q. How did your family member's relapse impact you personally?



Daily life aspects affected by relapse in a relative

Carers reported that a relapse in their loved one has a major impact on their own relationships with family and friends.

Q. Which of the following aspects of your daily life does your family member's relapse have an impact on?



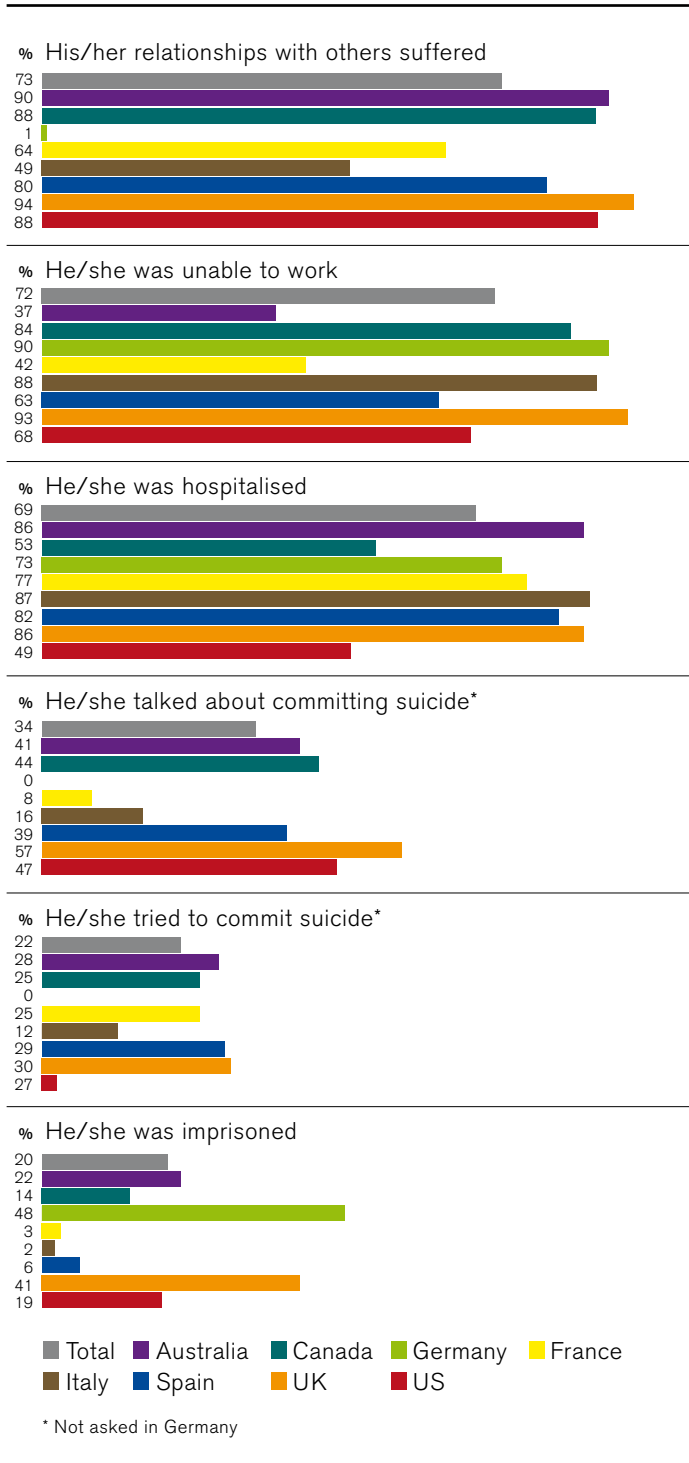
"A relapse is extremely difficult and disruptive for the family and often terrifying for the person being cared for. After an episode, the person may suffer from post-traumatic stress, as they recall their psychosis and feel the stigma attached to such an episode. Medication has helped to reduce the number of these episodes."

Alex Rivers, who cares for her family member, diagnosed with schizophrenia 18 years ago, on a daily basis. Alex is Vice-President of the Schizophrenia Fellowship of NSW.

Effects of relapse on the family member

Carers report that relapse has significant negative consequences for their family member. In Australia, relapse was most likely to result in an impact on the relative's relationships or in hospitalisation.

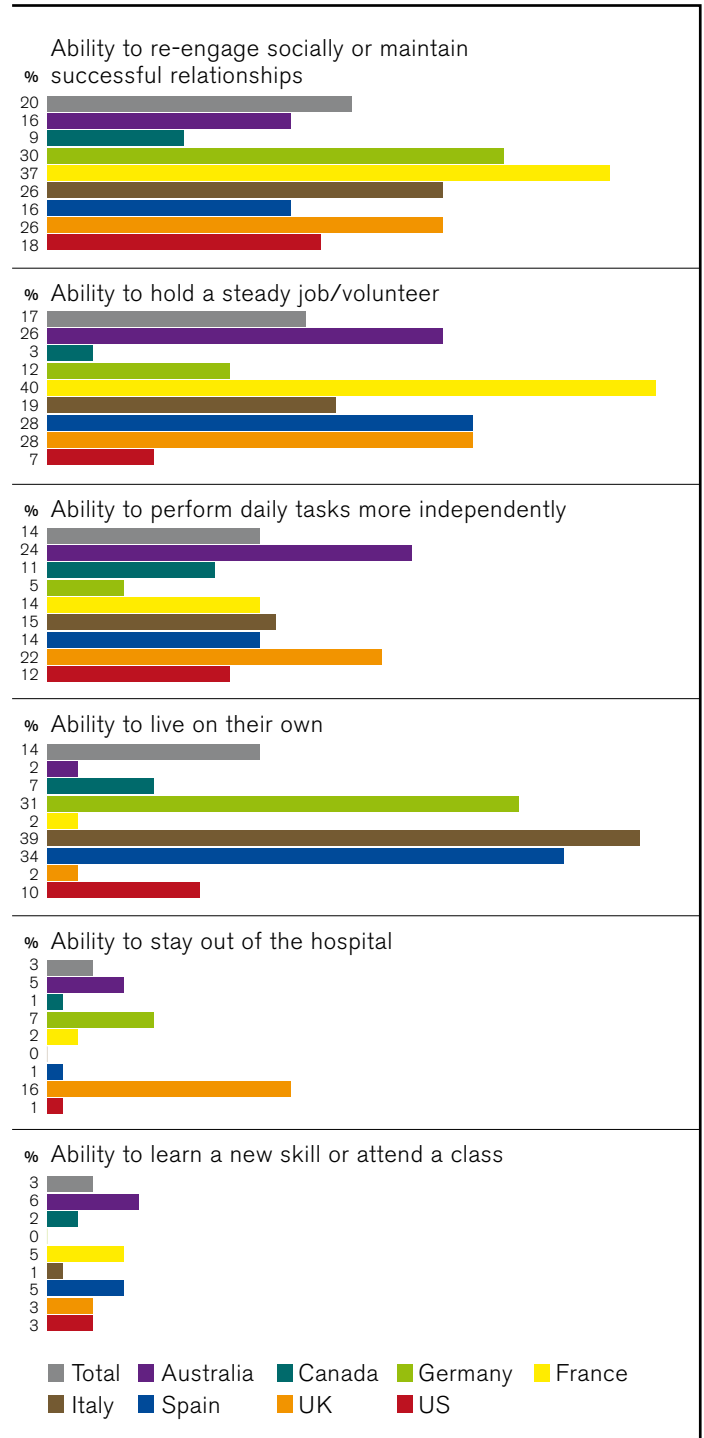
Q. Which of the following have happened as a result of your family member experiencing a relapse?



Carers' wellness objectives for family members

Carers around the world shared some common overall aspirations for their loved ones' lives, as shown in the graph below. In Australia, carers hoped their loved ones could develop greater independence.

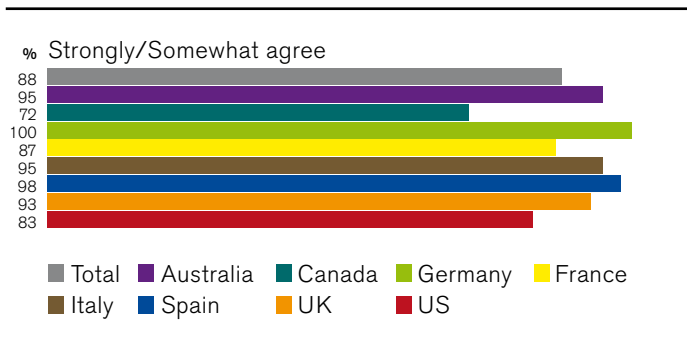
Q. In your opinion, what should be the wellness goal for your family member?



Symptom control a concern

Almost all carers agree that the worsening of their family members' symptoms is their major concern.

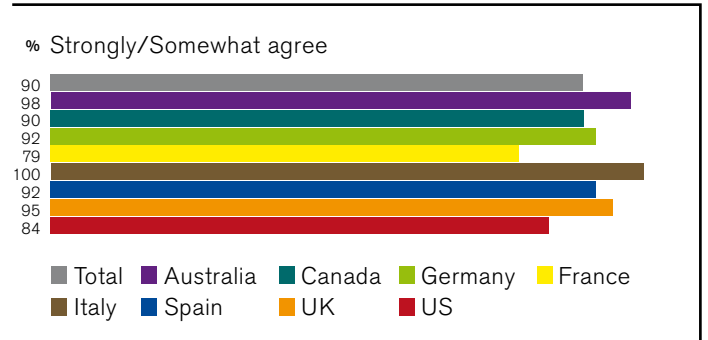
Q. How much do you agree or disagree that worsening of your family member's symptoms is your major concern?



Stopping medication causes family disruption

Carers from Australia almost universally agree that medication discontinuation leads to the disruption of family life.

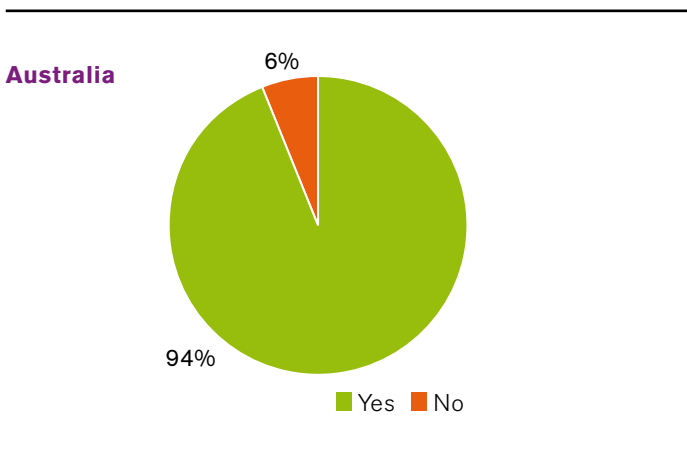
Q. To what extent do you agree that your family life was in any way disrupted as a result of your family member's discontinuation of medication?



Discontinuation and relapse

Of Australian carers surveyed, 94% believe discontinuing medication leads to relapse.

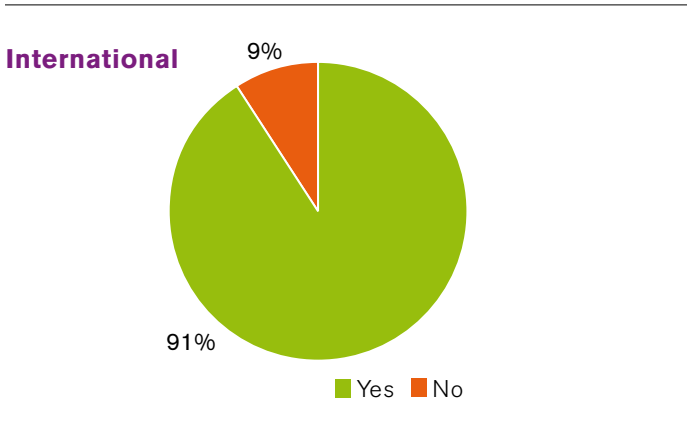
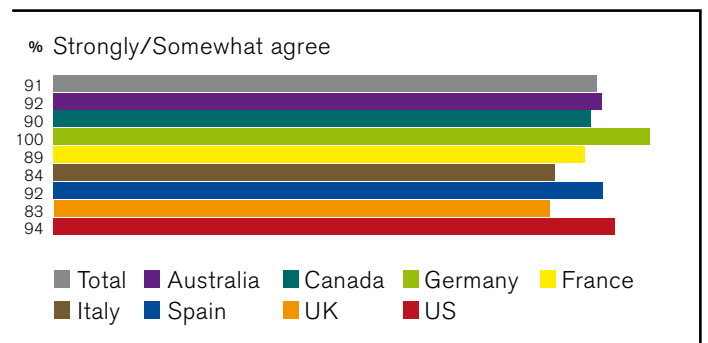
Q. Did discontinuation of medication ever lead to relapse, defined as worsening of symptoms and/or acute return of symptoms after apparent and/or partial recovery?



Efficacy is a primary concern

All caregivers agree that symptom control and management is their primary concern when considering treatment options.

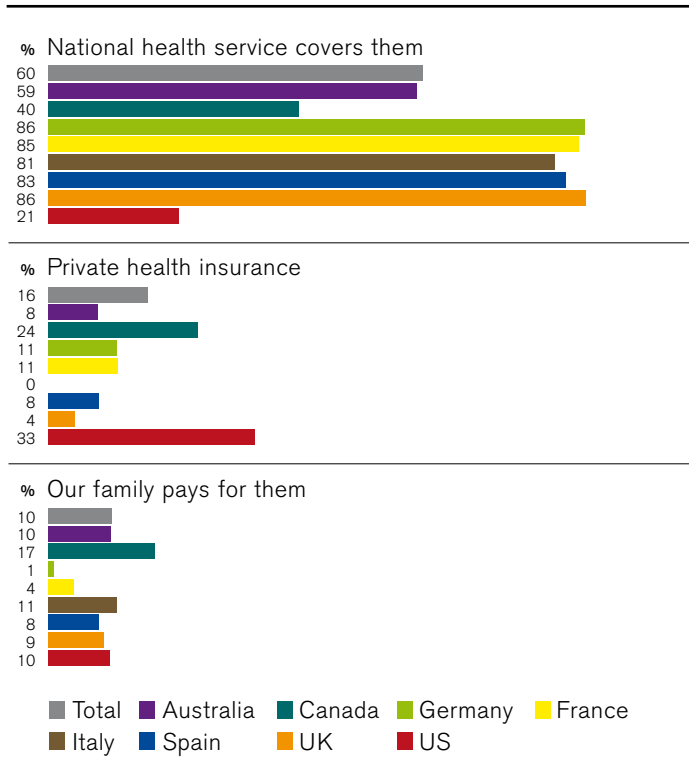
Q. How much do you agree or disagree that efficacy - defined as 'symptom control and management that enables your loved one to move forward with their life' - is your primary concern when considering treatment options for your family member?



Funding for health care

Australian carers were less likely than most other countries represented in the survey to report that government is funding health costs for their relative.

Q. How are the expenses for your family member's treatment and medication paid for?



“Once patients find a medication that works for them, it is important for them to stay on it. Attempts to save resources by limiting access to newer medications can fail when a switch to a different treatment, which may lead to treatment discontinuation and later trigger a relapse, ultimately increases costs for hospitalisation and other rehabilitative services. Before a switch is made, doctors have to weigh the risks and benefits of each treatment option while taking into consideration an individual's potential reaction to a new medication.”

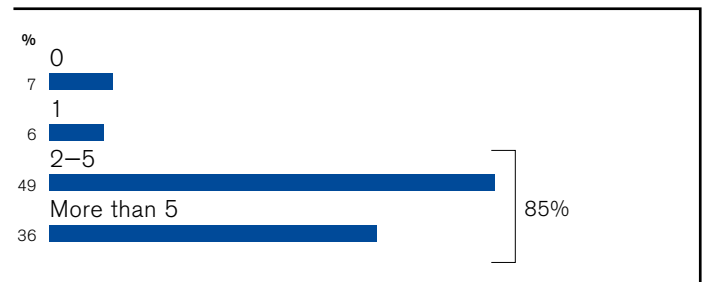
Prof. Dr. Dieter Naber
 Director of Department of Psychiatry
 and Psychotherapy
 University Medical Center
 Hamburg-Eppendorf, Germany
 (medical advisor for **Keeping Care Complete** survey)

Finding the right medication takes time

It is very common to try several medications before finding an effective one.

Q. How many different medications did your family member try before finding one that led to a marked improvement in his/her wellbeing and mental condition?

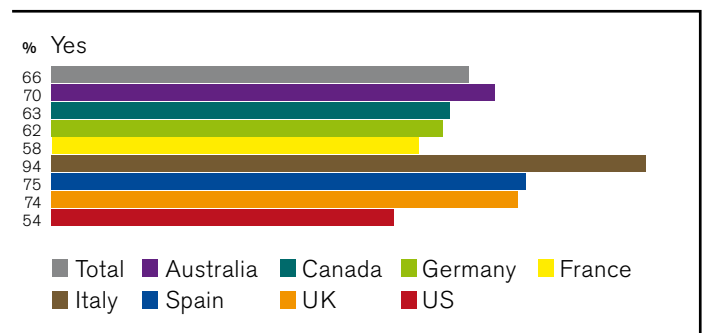
(Base: Satisfied with medication = 753)



Carers want doctors to focus on long-term treatment plans

Of Australian carers surveyed, a majority say they are frustrated by their loved one's doctor setting very low goals for long-term improvement.

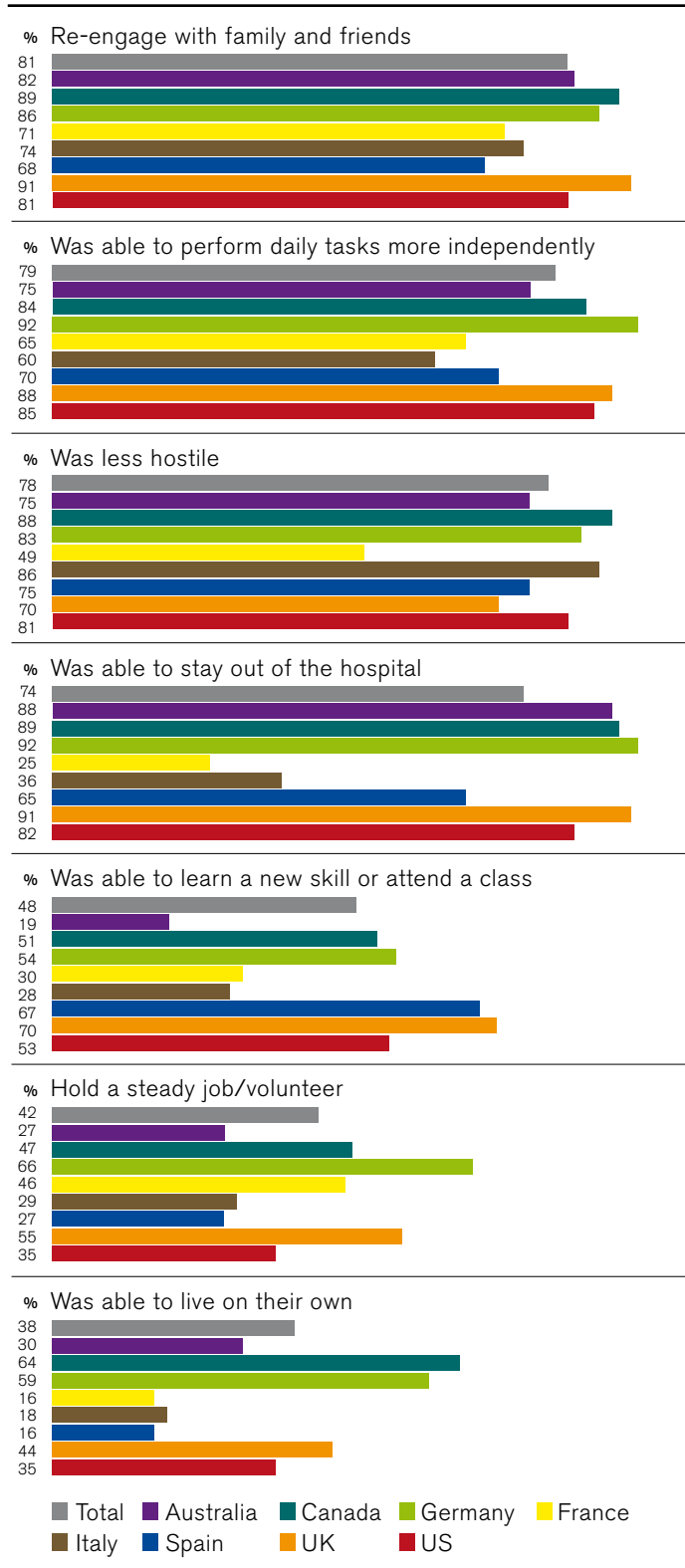
Q. Were you ever frustrated by a doctor's approach to set very low goals for long-term improvement of your family member's illness?



Accomplishments resulting from effective treatment

Re-engaging with friends and family is considered an important accomplishment by all carers surveyed, as this graph shows. In Australia, being able to remain out of hospital was the main benefit nominated.

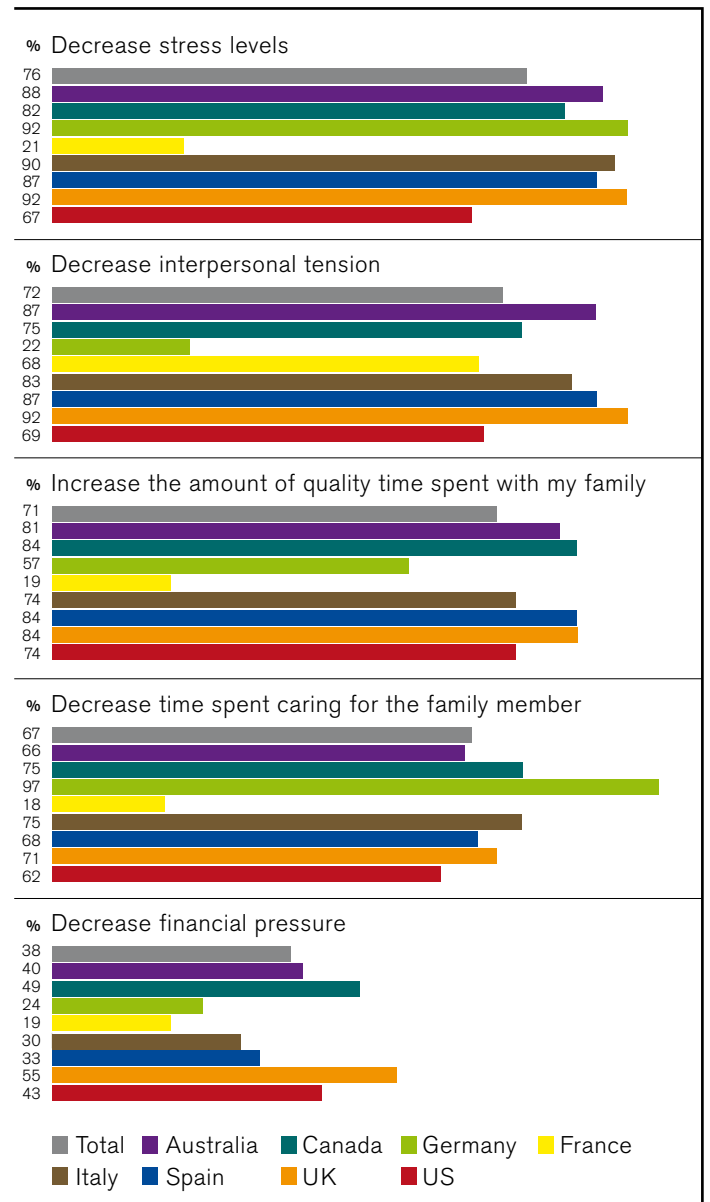
Q. What was your family member able to accomplish while being treated successfully?



Effects of successful treatment on family

Successful treatment works to decrease stress and tension for the family in Australia and most other countries surveyed.

Q. Please think about how your family member's wellness and improvement of symptoms have affected your family. Of the following, which have affected your family?



Further results

The following percentages represent answers for Australian respondents, with responses from the total international sample noted in brackets.

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:

- 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

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

The **Keeping Care Complete** survey was developed jointly by the World Federation for Mental Health and Eli Lilly and Company. The survey was conducted by independent market research company Ipsos-Insight in co-operation with All Global Ltd. All costs incurred in executing the survey and producing this report were met by Lilly.

For more information or additional results, please contact Eli Lilly Australia (Corporate Affairs), 112 Wharf Road, West Ryde NSW 2114, ph: 02 9325 4444.



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