

How was bipolarcaregivers.org developed?

Family members, partners and close friends of people with bipolar disorder (caregivers) sometimes do not have much information about dealing with the bipolar disorder of a loved one. Caregivers are at increased risk of experiencing distress, depression and other health problems. At the University of Melbourne we conducted research with the help of expert caregivers, clinicians and people with bipolar disorder (consumers) to develop guidelines and a website for caregivers giving information about bipolar disorder, ways to provide support, self-care and helpful resources.

Who helped develop the information on bipolarcaregivers.org?

One hundred and forty three caregivers, consumers and clinicians formed 3 expert panels (45 caregivers, 47 consumers and 51 clinicians). Panel members had experience in dealing with bipolar disorder and many had published in the area, conducted research on bipolar disorder or had public advocacy roles. Panel members were from Australia, USA, UK, Canada, New Zealand, Spain, Brazil, Portugal, Netherlands, Ireland, Norway and Denmark.

This study was part of a PhD project conducted by Lesley Berk under the supervision of Professor Anthony Jorm, Dr Seetal Dodd and Dr Claire Kelly in consultation with Professor Michael Berk. Funding came from a NHMRC PhD scholarship and a grant from the Department of Psychiatry at the University of Melbourne.



How was the information selected?

Panel members rated items on three online surveys on a 5-point scale from (1) 'essential' to include in the guidelines to (5) 'should not be included' in the guidelines'. Only items that gained very high levels of consensus amongst all three panels as being 'important' or 'essential' to include were accepted into the guidelines (see Box 1 for more details)

Box 1: Criteria for decisions about what to include in the guidelines:

The following consensus criteria were used to accept, re-rate or reject survey items:

Accepted items: Survey items were included when at least 80% of panel members in each of the three panels rated them as 'important' or 'essential' to include in the guidelines.

Re-rated items: Panel members were asked to re-rate items that 70%-79% of panel members in two of the panels, or 80% of panel members in one panel thought were 'important' or 'essential' to include in the guidelines. Before they re-rated these items, panel members were sent feedback about the overall previous rating of the three panels on these items.

Rejected items: Items with lower consensus levels than the above were deleted.

The items included in the first survey were based on information from the literature on bipolar disorder and 307 suggestions from panel members were subsequently added to the next survey. Of the 143 panel members who completed the first survey, 90 (33 clinicians, 27 consumers and 30 caregivers) participated in the second survey and 84 in the third (28 clinicians, 26 consumers and 30 caregivers).

Panel members are to be commended, not only for completing the detailed surveys, but also for the richness of their comments and suggestions. They emphasized that bipolar disorder is a complex illness and there are numerous different caregiving situations. Eventually 538 survey items were accepted into the guidelines; 86% of all survey items.

We considered that it may be easier for people to access information that is relevant to them on a website and bipolarcaregivers.org was born. The guidelines are also available as a PDF guide for caregivers on the bipolarcaregivers.org homepage.

Information summaries

Some survey items received between 95-100% endorsement by all three panels. Easy to print summaries based on topics raised in these items are available on the bipolarcaregivers.org homepage.

Artwork by people with mental health problems or their caregivers

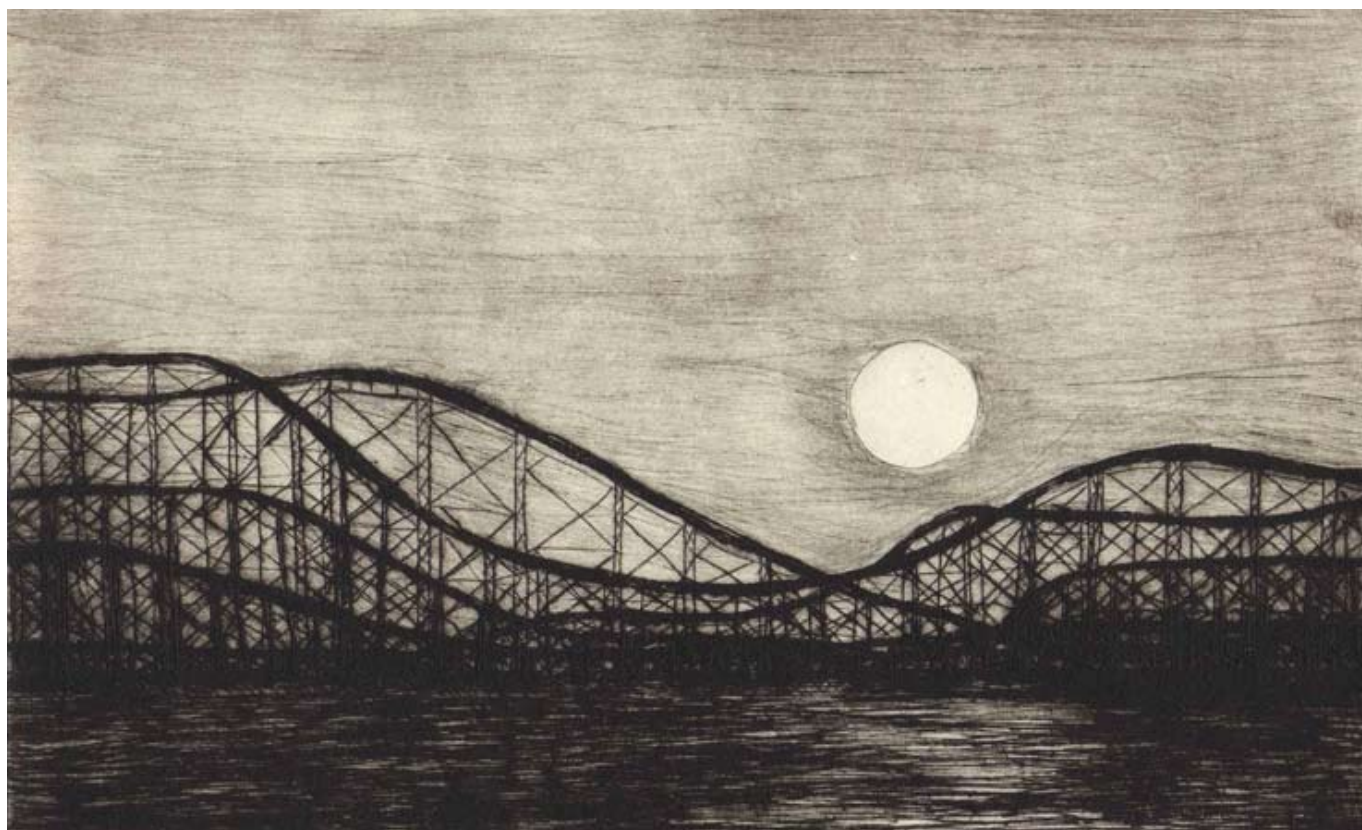
We invited people with mental health problems and their caregivers to submit artwork to help illustrate bipolarcaregivers.org and the PDF guide.

WE VALUE YOUR OPINION

We need your help as we continue to make this website useful for caregivers. There is a very brief feedback survey (takes less than 5 minutes to complete). You can access this survey by clicking the survey icon on the right hand side of the page or in the feedback section at the top of the website page before you leave the site.

There is also an additional follow-up survey especially for caregivers of people with bipolar disorder (takes between 5-10 minutes to complete). You can access this by completing the initial brief survey mentioned above or contacting Lesley on lberk@unimelb.edu.au.

Thanks,
All the best,
The bipolarcaregivers.org team



A Rollercoaster Life - Larissa MacFarlane



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Lesley Berk, Anthony Jorm, Claire Kelly, Michael Berk, Seetal Dodd and the clinicians, caregivers and people with bipolar disorder who helped to develop this guide.