

Mental Health Carers Survey 2010

If you care for someone with a mental illness then you are a mental health carer.

Thank you for agreeing to be part of the Mental Health Carers' Survey 2010. The survey forms part of an ongoing project to find out about the lives of mental health carers during the previous 12 months. Your response will form part of the first annual Mental Health Carers' report which will be presented to the government in October 2010.

The survey is based on the top 15 issues identified by over 1,500 mental health carers detailed in *'Adversity to Advocacy, the lives and hopes of mental health carers'*. If you care for more than one person with a mental illness please complete one survey for each person you care for. Please include as many contact details as you feel able to. We need to be able to contact you again to complete the annual surveys. Your responses will be treated in confidence. Meaning that no individual will be identified in any reported findings. Please feel confident to complete the survey as fully as possible and be part of the annual Mental Health Carers' Survey. (*an asterisks means this question is very important so please answer it*)

Thank you for participating!

1. Please complete the following details about you, the carer.

First Name

Last Name

Street Address

Town/City

State

Post Code

Email address

Phone number (including area code)

Mobile Number

2. *Gender* Male Female

3. *Year of birth*

4. *What is the main language you speak at home? (please tick)

English Other (which language)

5. *Do you identify as an Aboriginal or a Torres Strait Islander person* Yes No

6. *What was your approximate gross (before tax) household income for the 2009/2010 financial year* (Please enter as a whole number e.g. 30,000)

7. *How many people with a mental illness do you care for?*

In the following questions we will refer to a person with a mental illness as a consumer.

If you care for more than one person with a mental illness (consumer) please complete one survey for each consumer or answer this survey in relation to only one person.

8. Which consumer are you completing this survey for (tick one)?

Daughter / son under 18

Parent

Daughter / son over 18

Grandparent

Sibling

Grandchild

Partner

Friend / other person (please specify)

Other family member (please specify)

9. *How long have you been caring for the consumer* (please enter approximate years eg 3.5 years) _____

10. Does the consumer have more than one disorder, condition or disability?

- Yes No (please got to question 12)

11. If yes what is the nature of that disorder, condition or disability (tick all that apply)?

- Drug and Alcohol issues Eating Disorder
 Intellectual disability Diabetes
 Acquired brain injury Other, please give details _____
 Physical disability

12. Please indicate (with one tick in each row) how much each of these people listened to your concerns about the consumer during the last 12 months.

	Always listens	Mostly listens	Sometimes listens	Rarely listens	Never listens	Not applicable
Psychiatrist						
Psychologist						
GP						
Mental health nurse						
Community worker						

13. During the last 12 months how much have you been made to feel part of the 'caring team' by the mental health professionals involved in the care of the consumer?

- Never
 Rarely
 Sometimes
 Mostly
 Always

14. If you have further comments on this issue please add them here

15. Were any of the following recovery based care options available to the consumer during the last 12 months?

	Available	Not available	Don't know
Club house			
Living skills			
Supported employment / training			
Personal helpers and mentors (PHaM's workers) / support worker			
Peer support workers			
Day programme			
Other			

16. Who organised the majority of the non-medical care for the consumer during the last 12 months (tick all that apply)?

- Medical worker
 Community worker
 Me or a close family member
 Other, please give details _____

17. During the past 12 months has the information you needed to help you care for the consumer been easily available? (Consider the information provided by Centrelink, housing as well as medical professionals.)

- Always available
- Mostly available
- Sometimes available
- Rarely available
- Never available

18. During the last 12 months has the information you needed to help you care for the consumer been offered at the right time?

- Always
- Mostly
- Sometimes
- Rarely
- Never

19. During the last 12 months where have your sourced information to help you care for the consumer (tick all that apply)?

- | | |
|--|---|
| <input type="checkbox"/> Psychiatrist | <input type="checkbox"/> Internet |
| <input type="checkbox"/> Psychologist | <input type="checkbox"/> Carer services |
| <input type="checkbox"/> GP | <input type="checkbox"/> Centrelink |
| <input type="checkbox"/> Mental health nurse | <input type="checkbox"/> Housing |
| <input type="checkbox"/> Community worker | <input type="checkbox"/> Triage / helplines |
| <input type="checkbox"/> Bilingual worker | <input type="checkbox"/> Police |
| <input type="checkbox"/> Aboriginal worker | <input type="checkbox"/> Social worker |
| <input type="checkbox"/> Drug and alcohol worker | <input type="checkbox"/> Counsellor |
| <input type="checkbox"/> Pharmacist | |
| <input type="checkbox"/> Other (please give details) _____ | |

20. How well do you think carer and consumer issues are understood by the following professionals (tick all that apply)?

	Extremely well	Very well	Quite well	A little	Not at all well	Don't know
Psychiatrist						
Psychologist						
GP						
Mental health nurse						
Community worker						
Bilingual community worker						
Aboriginal worker						
Drug and alcohol worker						
Pharmacist						
Carer Services						
School staff						
Housing officials						
Triage / helplines						
Centrelink staff						
Prison staff						
Court officials						
Police						
Social workers						
Counsellors						

21. If you have further comments on this issue please add here.

22. Have the following services been available to you over the last 12 months?

	Always	Mostly	Sometimes	Rarely	Never	Not available in my area	Don't know/not required
Carer support groups							
Pharmaceutical drug information							
Information on how to help the consumer							
Carer counselling							
Carer respite							
Internet based services							

23. Please comment on the quality of the services available to you over the last 12 months.

	Excellent	Good	Average	Poor	Very poor	Not available in my area	I haven't used them
Carer support groups							
Pharmaceutical drug information							
Information on how to help the consumer							
Carer counselling							
Carer respite							
Internet based services							

24. When the consumer was extremely unwell during the last 12 months were the following services available? (If the consumer has not been extremely unwell in the last 12 months please go to question 26.)

	Always	Mostly	Sometimes	Rarely	Never	Not known by me
24 hour emergency outreach team						
Quick response from 24 hour outreach team						
Consumer activity encouraged and available in acute service						
No early discharge						
Discharge plan discussed with carer before discharge						
Information and assistance offered to carer by acute medical staff						
24 hour emergency telephone line						
Assistance with language and translation						
Detox services						
Case worker accessible when needed						
Information as to where the consumer had been taken offered within 12 hours						

25. Were the acute services beneficial to the consumer's health during the last 12 months?

- Always
- Mostly
- Sometimes
- Rarely
- Never
- No acute services were accessed

26. *How far do you travel to access specialist mental health services (eg acute care) for the consumer*

- Less than 20 kilometres
- 20–49 kilometres
- 50–99 kilometres
- 100–199 kilometres
- 200–499 kilometres
- 500–999 kilometres
- 1,000–2,000 kilometres

27. If you have further comments about services please add here.

28. What has been the extent of stigma and discrimination around mental illness in your local community during the last 12 months?

- Stigma and discrimination are widespread
- Stigma and discrimination exist to some extent
- Stigma and discrimination do not exist

29. What was been the extent of stigma and discrimination around mental illness in the wider Australian community during the last 12 months?

- Stigma and discrimination are widespread
- Stigma and discrimination exist to some extent
- Stigma and discrimination do not exist

30. Have you felt alone in your role as a mental health carer in the last 12 months?

- Always
- Often
- Sometimes
- Rarely
- Never

31. How helpful have the following people been in making you feel less alone in the last 12 months?

	Extremely helpful	Very helpful	Quite helpful	A little helpful	No help at all	Not relevant
Family						
Close friends						
Carer support groups						
Carer organisations						
Internet forums						
Spiritual or religious beliefs						

32. Where has the consumer lived during the last 12 months (tick all that apply)?

- | | |
|---|--|
| <input type="checkbox"/> With me | <input type="checkbox"/> Private unsupported accommodation |
| <input type="checkbox"/> With other family | <input type="checkbox"/> Acute care facility/hospital |
| <input type="checkbox"/> Independently | <input type="checkbox"/> Step up/step down facility |
| <input type="checkbox"/> Supported independent living | <input type="checkbox"/> Prison |
| <input type="checkbox"/> Group home | <input type="checkbox"/> Residential rehabilitation |
| <input type="checkbox"/> Hostel | <input type="checkbox"/> Unsure |
| <input type="checkbox"/> On the street | <input type="checkbox"/> Other _____ |
| <input type="checkbox"/> Public unsupported accommodation | |

33. Which of the following accommodation options were available in your area during the last 12 months (tick all that apply)?

- | | |
|---|--|
| <input type="checkbox"/> Supported independent living | <input type="checkbox"/> Public unsupported accommodation |
| <input type="checkbox"/> Group home | <input type="checkbox"/> Private unsupported accommodation |
| <input type="checkbox"/> Hostel | <input type="checkbox"/> Residential rehabilitation |
| <input type="checkbox"/> Step up/step down facility | <input type="checkbox"/> Unsure |

34. If you have further comments on issues of accommodation please add here.

35. Have you applied for any of the following during the last 12 months?

	Not applied for	My application has been rejected	Am an existing recipient	Not used
Carer payment				
Carer allowance				
Travel costs to remote hospital				
Carer accommodation costs to access remote hospital				

36. We know that many carers support the consumer financially. Please estimate the average amount (in dollars) you provide or spend on the consumer each fortnight (eg costs of transporting consumers to activities and appointments etc.)

\$

37. Please indicate which of the following coping strategies or services you have used during the last 12 months (include details of any associated costs/subsidies)?

	100% of cost	Subsidised cost	Free carer service	Not used
Sleeping pills				
Anxiety medication				
Anti depressants				
Counselling				
Massage				
Acupuncture				
Gym membership				
Respite / time out				
Holiday				
Other				

38. As a result of being a mental health carer do you consider your physical or mental health has changed during the last 12 months?

- My health is much worse
- My health is slightly worse
- There has been no change to my health
- My health is slightly better
- My health is much better

39. Do you ever use carer respite services (tick all that apply)?

- I do not know what carer respite services are
- I use carer respite regularly
- I could not leave the consumer with a respite worker
- Carer respite is not offered in my area
- What I need from respite care is not available
- I am not aware of any carer respite services being available
- I do sometimes use carer respite services
- I do not need carer respite services

40. If you have further comments on carer respite please add here.

41. During the last 12 months were the privacy and confidentiality of the consumer used by staff to exclude you from information you needed to be able to provide proper care?

- I was always included
- I was included some of the time
- I was sometimes included and sometimes excluded
- I was mostly excluded
- I was always excluded

42. Please comment on the availability of information about the consumer's medication and illness during the last 12 months.

	Always	Mostly	Sometimes	Rarely	Never
Consumer medication and prescribing routine					
Medication side effects					
What to expect from the mental illness					
How to care better					

43. How much concern and anxiety about the consumer's health and welfare have you experienced because of the lack of disclosure from the mental health professionals involved with the care of the consumer?

- None
- Small amount
- Moderate amount
- Large amount
- Extreme amount

44. Were you included in the planning of the consumer care plan?

- Yes
- No
- I do not know what a care plan is

45. If you have further comments on this issue please add here.

46. If the consumer was unwell during the last 12 months how satisfied were you with the response from mental health services in order to prevent an acute episode of illness?

- Extremely satisfied
- Quite satisfied
- Not satisfied or dissatisfied
- Quite dissatisfied
- Extremely dissatisfied
- The consumer has been well during the last 12 months

47. If there has been an improvement during the last 12 months in access to early intervention care for the consumer, who was responsible for that improvement (tick all that apply)?

- | | |
|--|--|
| <input type="checkbox"/> There has been no improvement | <input type="checkbox"/> Aboriginal worker |
| <input type="checkbox"/> Psychiatrist | <input type="checkbox"/> Bilingual worker |
| <input type="checkbox"/> Psychologist | <input type="checkbox"/> Drug and alcohol worker |
| <input type="checkbox"/> GP | <input type="checkbox"/> School staff |
| <input type="checkbox"/> Mental health nurse | <input type="checkbox"/> Police |
| <input type="checkbox"/> Community worker | <input type="checkbox"/> Case manger |
| <input type="checkbox"/> Other (please give details) _____ | |

48. Please comment on the statement "In the last 12 months my workplace was more understanding of my needs as a mental health carer".

- Strongly agree
- Agree
- No change
- Disagree
- Strongly disagree
- I am not in the workforce
- I am retired

49. Please comment on the statement "In the last 12 months the flexibility within my workplace to assist me as a mental health carer improved".

- Strongly agree
- Agree
- No change
- Disagree
- Strongly disagree
- I am not in the workforce
- I am retired

50. If you have any final comment please write here

Thank you for being part of the mental health carer survey 2010

Your response will become part of the 2010 Australian Mental Health Carers' Report. The report is based on the survey and will be available on the MHCA website in November 2010 at www.mhca.org.au