

---

# It goes with the Territory!

## The views of ACT Women who are Mental Health Carers about Health and Wellbeing Information

A Companion Report to *It goes with the Territory! ACT Women's views about Health and Wellbeing Information (July 2010)*

---

**Angela Carnovale**

April 2011

---

# **It goes with the Territory!**

## **The views of ACT Women who are Mental Health Carers about Health and Wellbeing Information**

*A Companion Report to *It goes with the Territory! ACT Women's views about Health and Wellbeing Information (July 2010)**

---

**Angela Carnovale**

April 2011

# ACKNOWLEDGEMENTS

---

Thanks to Claire from Carers ACT for inviting and supporting women to participate in the focus group and thanks especially to the five women who gave their time to contribute their insights, experiences and opinions to this research. We hope that through documenting your stories your health and wellbeing information needs will be better met in the future.



## **Publication/Copyright Information**

ISBN 978-0-9586279-9-3 |

© 2011 Women's Centre for Health Matters Inc.

Published by Women's Centre for Health Matters Inc.

This publication is protected by copyright. Apart from any use permitted under the *Copyright Act 1968*, no part may be reproduced without acknowledgement.

### **About Women's Centre for Health Matters Inc.**

The Women's Centre for Health Matters Inc. (WCHM) is a community based organisation which works in the ACT and surrounding region to improve women's health and wellbeing. WCHM believes that the environment and life circumstances which each woman experiences affects her health outcomes. WCHM focuses on areas of possible disadvantage and uses research, community development and health promotion to provide information and skills that empower women to enhance their own health and wellbeing. WCHM undertakes research and advocacy to influence systems' change with the aim to improve women's health and wellbeing outcomes. WCHM is funded by ACT Health. The findings and recommendations of this report are those of WCHM and not necessarily those of ACT Health.

### **About the Author**

Angela is the Social Research Officer at WCHM, and has completed a Bachelor of Arts and Asian Studies at the Australian National University.

<b>EXECUTIVE SUMMARY</b>	<b>4</b>
<b>RECOMMENDATIONS</b>	<b>6</b>
<b>INTRODUCTION</b>	<b>8</b>
<b>FOCUS GROUP FINDINGS</b>	<b>9</b>
1.1    GOOD QUALITY HEALTH AND WELLBEING INFORMATION	9
1.2    INFORMATION SOURCES	11
1.2.1    General Practitioners	11
1.2.3    Internet	13
1.2.4    Mass Media	14
1.2.5    Paper Based Publications	15
1.2.6    Family Members and Friends	15
1.2.7    Other Sources	16
<b>DISCUSSION</b>	<b>17</b>
<b>CONCLUSION</b>	<b>21</b>
<b>REFERENCES</b>	<b>22</b>

# EXECUTIVE SUMMARY

---

Women are the primary seekers of health and wellbeing information in the ACT, not only for themselves, but also for their children and other family members, yet they face significant challenges. When women have access to appropriate health and wellbeing information they are able to make informed choices about their own and their family's health and access services and support relevant to their needs.

Since women are the main family decision makers for health issues and the main family carers, their access to appropriate health and wellbeing information is crucial. They need to be able to make informed choices about their own and their family's health, and access relevant services and support. Unfortunately, there is scant research identifying ACT women's needs and preferences in relation to health and wellbeing information; the ways in which they appraise information; the barriers that restrict them from accessing information; and the gaps in their information landscape.

In the ACT, we are facing a chronic shortage of GPs, clinic closures, redefinition of the roles of pharmacists and nurse practitioners and federal reform of primary and community based healthcare systems. This changing external environment and the increasing complexity of health information means that women face significant challenges in identifying credible and trustworthy information, and this in turn impacts on their ability to maintain good health and wellbeing.

It is for these reasons that research was commissioned by the Women's Centre for Health Matters (WCHM) to explore the views and preferences of (different groups of) ACT women in accessing health and wellbeing information and how this information is transformed into knowledge. Women's views and personal stories were sought through a variety of media—a survey (674 responses), seven focus groups and a follow-up survey. This primary data was then supplemented by an extensive literature review.

The findings of the *It goes with the Territory!* report were consistent with previous research undertaken by WCHM and demonstrated that women's access to health and wellbeing information can be affected by their social and economic circumstances: the social determinants of health. ACT women want information to be *available, affordable, accessible* and *appropriate*. These 'four A's' form the basis of WCHM's definition of gender sensitive health service delivery and are integral to maintaining good health and wellbeing.

Because the data gathered was so rich, WCHM decided to accompany the *It goes with the Territory!* report with companion reports highlighting the needs and preferences of particular groups of women in the ACT, as these companion reports showed that there is as much diversity between different groups of women as there is between women and men.

This companion report represents the views of the five ACT women who are mental health carers who participated in a focus group with WCHM. The report does not include any data from the original health and wellbeing information survey because respondents were not asked to identify whether or not they have caring responsibilities for a person with a mental health issue. Therefore there is no data that can be used to complement the focus group discussion.

In an environment where governments are increasingly required to provide economic responses to the provision of health and social services, accessible health and wellbeing information would strengthen women's self-management and play a part in reducing women's reliance on the health system. Women with knowledge of available options are better equipped to use the ACT health care system effectively; especially in understanding what issues can be dealt with at home, how best to deal with issues, and when to contact a health care provider. Good quality health and wellbeing information can successfully substitute consultations with health professionals, which can increase a woman's autonomy and save her money.<sup>1</sup>

It is WCHM's hope that this companion report will improve the understanding of the needs of women who are mental health carers in the ACT in order to facilitate health and wellbeing information provision that is responsive to their needs.

This report makes a number of recommendations that were developed through consultation with the women and organisations that participated in the research, the WCHM Board of Directors and WCHM staff.

---

<sup>1</sup> Murphy, M., Murphy, B. & Kanost, D., *Access the Women's Health Information: A Literature Review of Women as Information Seekers*, Women's Health Victoria, Melbourne, 2003, p. 8.

# RECOMMENDATIONS

---

The overall recommendations from WCHM's research were:

- WCHM to work with ACT Health to identify how to actively promote alternatives to GPs and to explain the tiered levels of intervention that are available in the ACT (in particular Walk-in Centres, pharmacists, nurses, practice nurses, nurse practitioners, CALM services, HealthDirect, and the hospital emergency departments) to increase the awareness of and trust by ACT women, with a particular focus on information on each about:
  - Their scope of practice;
  - confirmation of their qualifications and skills; and,
  - when to use them or access them.
- WCHM to work with ACT Health in relation to the GP Taskforce recommendation on the development of a GP Register and to ensure the incorporation of feedback from ACT women.
- WCHM to work with ACT Health to consider the issues raised by women about the ACT Health website and white pages entries, and the need for better navigation about the range and scope of available services for women in the ACT.
- WCHM to advocate with ACT Government about the need to continue to explore, pilot and evaluate new community based primary care that is supplementary to both GP practices and hospital emergency departments and which meets women's needs, including tiered approaches which also use technologies such as health information lines and Internet sites.
- WCHM to develop its website (working in partnership with key stakeholders and women) to provide assistance to ACT women in navigating and assessing the information that is accessed through the Internet, particularly through:
  - the provision of tools to support ACT women to understand how to assess and identify trusted sites—by enabling women to access trusted information they will be able to make more rational and informed health decisions without needing to access GPs to verify information;
  - the use of navigation tools to assist them to find their way around the health system and to access services in and outside the health system that lead to better health outcomes;
  - the development and trialling of a central approach to health and wellbeing information in the ACT for women with a focus on the current gaps identified (Having a baby in Canberra, sexual health and menopause for older women, and young women and eating disorders).

To represent the issues specifically raised in this companion report by women who are mental health carers in the ACT, WCHM will:

- Undertake further work to develop a profile of the health and wellbeing needs of women who are mental health carers in the ACT.
- Work with Mental Health ACT and Carers ACT to promote the needs of women who are mental health carers among health and community service providers.
- Advocate with ACT Health and Mental Health ACT about the need to develop pathways to *available, affordable, accessible and appropriate* information for women who are mental health carers, which addresses:
  - the inconsistencies in mental health information in the ACT;
  - the barrier of cost and how this barrier reduces the number of accessible information sources for women mental health carers; and
  - policies not being reflected in practice.
- Work with partners to identify potential funding and develop an innovative online peer support model for women who are mental health carers in the ACT.



# INTRODUCTION

---

Mental health carers are a group who face unique challenges in accessing health and wellbeing information. Their needs are currently unmet by the policies in place to meet them, and the barriers they face are steadfast.

Mental health carers occupy a difficult space between the person they care for, mental health workers and the social stigma surrounding mental illness; unable to access relevant and timely information and therefore sometimes curbed in their caring role. This is not an original finding. The Mental Health Council's *Adversity to Advocacy*<sup>2</sup> report, released in October 2009, documented, in consultation with mental health carers from around Australia, the fifteen most common issues affecting mental health carers.

Several of the fifteen issues identified in *Adversity to Advocacy* were echoed throughout a focus group with mental health carers, conducted by WCHM as part of their study into ACT women's views about health and wellbeing information. These were: the need to listen to and increase respect for carers; improved access to knowledge and information for carers; education of service providers on the role and importance of carers; better resourcing of mental health carer organisations; reduction in stigma, discrimination and isolation for carers and consumers; recognition of financial burden to carers; and privacy and confidentiality issues.

The focus group covered a wide terrain, from opinions on pamphlets as a mental health information source, to personal accounts of interactions with mental health professionals and services. The women had been invited to discuss their own health and wellbeing information needs, but unlike the participants of other focus groups, the women focussed on the information they require to fulfil their caring role. For these women, the needs of the person they care for drives their search for health and wellbeing information.

This companion report lays out the findings of the focus group, and discusses the main themes that emerged throughout it. The findings do not comprehensively reflect the information sources or issues that were investigated in the WCHM health and wellbeing information survey, but reflect those information sources or issues that were specifically discussed during the focus group. The report does not include any data from the original health and wellbeing information survey because respondents were not asked to identify whether or not they have caring responsibilities for a person with a mental health issue. Therefore there is no data that can be used to complement the focus group discussion.

---

<sup>2</sup> Mental Health Council of Australia, *Adversity to Advocacy: The Lives and Hopes of Mental Health Carers*, Mental Health Council of Australia; Canberra, 2009.

# FOCUS GROUP FINDINGS

---

## 1.1 GOOD QUALITY HEALTH AND WELLBEING INFORMATION

The participants were asked what they thought good quality health and wellbeing information to be. Similar to other focus group discussions, ease of accessibility, clarity and simplicity in language and reliability were some initial characteristics. There were, however, some imperative qualities of good health and wellbeing information that had not been discussed by other groups.

The first of these was that the information from one source does not conflict with information from another source. Several of the participants stated that it is possible to seek information for a particular issue from several different sources and receive completely different, sometimes conflicting, information. One participant thought that this trend could be particular to mental health information as there is a high level of opinion charged care and information provision. She felt that there is a subjective element that makes the information change slightly from source to source.

Two examples of this emerged throughout the discussion. The first was when one participant said that she would like GPs to have a list of psychologists that can be used for referral for the Mental Health Care Plan, with another participant advising that one such list already exists. A second example of this was raised later in the discussion about a contact book for mental health services in the ACT. One participant had this particular book, which another had never seen before. A third participant commented that this contact book, along with some other standard information about mental health, is supposed to be distributed when an individual first approaches a health professional about a mental health issue, which demonstrates the inconsistency in available information. When asked if the participants interpreted this inconsistency as insensitivity toward carers, one participant responded...

*I don't think it's a lack of sensitivity. Their loyalty must be first to the patient, and there may be a conflict between the interests of the client and that of the carer and if they are skilled they will be able to manage that conflict.*

The second characteristic of good quality health and wellbeing information is that it be personalised. This characteristic was important to most of the participants of the WCHM focus groups; however, the participant who raised this issue identified this as "having access to the same information (as a carer) as the person you are caring for." She reported having been unable to get information from health professionals because of the mature age of the person for whom she cares, but also being unable to get information from this person. She experienced difficulty understanding the level of information that health professionals will give and felt that from counsellors, to psychologists, to psychiatrists each views their role as information provider very differently. She was surprised by the lack of assistance from these workers in helping her

to understand her loved one's health issues, which was a barrier to the effectiveness of her care.

Availability of information was the third major concern for the participants. One participant explained that because the care recipient does not always acknowledge that they require care, mental health carers need to be armed with good quality information about treatments and services for the moment the recipient decides that they need or want help. This means that mental health carers need ongoing access to good quality and up-to-date information to keep on hand.

The WCHM definition of good quality health and wellbeing information is that it: increases an individual's knowledge about health, wellness, illness and disease; assists an individual in making choices about their lifestyle and decisions about their health; and reduces anxiety about health issues. The participants agreed that parts one and three are appropriate; however, they thought that the second point only applies to individuals with the power and ability to choose change and make decisions. One participant succinctly commented "dream on—some people are not capable of making lifestyle changes, with or without good quality health information".

## 1.2 INFORMATION SOURCES

### 1.2.1 General Practitioners

The primary frustration expressed by several participants was that GPs often provide information which conflicts with information provided by other mental health professionals. One participant felt that GPs wear “rose coloured glasses” and assume that if the client has been provided with medication and is functioning normally at the consultation, then they are suitably taken care of.

It may be that GPs do not have sufficiently in-depth knowledge or experience in dealing with individuals with mental health issues. One participant shared a story of a GP she used to see—who she regarded as a very good GP—who on one occasion said to her “my daughter’s boyfriend has just been diagnosed with schizophrenia, now you’ve gotta tell me all about schizophrenia.” When asked if this makes GPs untrustworthy, one participant replied, “you can trust that they have sincerely given you [the information]...they’re not being deceptive. But it can be conflicting with other pieces of information.”

Another participant lamented the difficulty of finding a GP in Canberra, the improbability of having a continuing relationship with a single GP and the rareness of GPs with mental health expertise. She acknowledged that “looking at the total person and giving each person the time” is something that “GPs don’t have the time to do.” When asked how someone could find a GP in the ACT with mental health expertise she replied, “I don’t know, how do you find [one]?” Another participant responded that it is likely that such a GP would be identified through peers, but that it would be virtually impossible to have the person they are caring for accepted as a new patient. She felt that many doctors are not prepared to say that they treat people with mental health issues as they know they will be overwhelmed.

Two participants felt more optimistic about the role of the GPs, despite the challenges they sometimes face in dealing with them. For one of the participants, the GP was integral in watching over the general health of her loved one, which she thought was not the concern of the many mental health professionals. Another participant responded to this, highlighting the positive and negative aspects of the GP approach to mental health issues...

*I think that they really do try to help but...they operate from a very different paradigm, it's not this sort of, everything's complex...it's let's reduce it down to the simplest thing we can do. And...that is useful, but, you know, in terms of the unexpected things that can happen, the misinformation, the friction, those are the downside.*

### 1.2.2 Psychologists, Social Workers and Counsellors

Mental health workers and professionals were the main information source discussed in the focus group.

The extent to which mental health workers and professionals view their role as encompassing information provision created a considerable amount of confusion among some of the participants. One participant said that she had the view that her psychiatrist would fulfil the role of information provider, which the psychiatrist did not share. “I mean, I’m not sure what their role is; is their role just to hand out the medication and that’s it?” She said that not being able to obtain information from psychiatrists—which she assumed was because of confidentiality restrictions—made her feel deliberately shut out of information provision.

Another participant agreed that clients often do not know what questions to ask and therefore, health professionals could endeavour to preempt the information needs of clients and carers but often don’t, providing only the most minimal information. She thinks that case workers are ideally placed to be information providers, and yet she has found them unwilling, despite having been told that she was “lucky to have one”.

One participant explained that in her experience social workers were more willing to play the role of information provider. She said that the “social workers are a really good half way house. They seem to be aware of what the shortcomings are and our side of the picture.” She explained that they often have a much more integrated understanding of mental health and understand, for example, that having a home is integral to good health and that people with mental health issues are susceptible to homelessness. Social workers therefore have a much greater knowledge about Centrelink, legal services and other institutions that people with mental health issues may have contact with.

*Whilst the medical professionals hide behind the policies, the dear little clients hide behind their illness to try and get away with atrocious behaviour that they could control...and when you’ve got social workers and nurses lower down on the chain who are observing them more closely, you get a more realistic feedback...that you are on the right track.*

The other participants were asked if they too had found the social workers to be useful, to which two of the participants responded “I don’t know, how do you get to see a social worker?” The first participant responded to this, “once again, luck. You’ve just gotta be in the right place at the right time.”

Several of the other participants were interested in seeing a social worker but had not yet had the opportunity. One participant said, “over the years I’ve thought about it and I’ve sort of thought ‘well why didn’t the hospital introduce me to a social worker,’” to which another participant agreed. The first participant continued that in the early days she waited for someone to ask if she would like to see a social worker, or to present her with a range of options, which did not happen. She said that initially she was in a daze and really needed someone to provide the information that she did not know she was looking for. She said, “I think sometimes there is a perception amongst hospital workers that if you look as though you can manage, then you just go out into the world and manage by yourself.” She explained that her family were provided a

social worker when her daughter was in hospital with severe burns, but never when her daughter was in the psychiatric ward.

That having been said, this participant was eager to share a good news story about the psychiatric services unit.

*I can say, against all of the horror stories that I've ever been told about PSU, that my daughter was taken there in an involuntary capacity and she was in a very bad way when she went there, they really did care for her awfully well. I would say that the conditions there are Dickensian, and the staff work in the most appalling situations, but when the doctors came to their conclusion, and when they thought they had the right diagnosis, we were called in as a family, and we had an hour and a half, and they told us what they had discovered and the reasons why and that there would be a referral on and they gave my daughter equal time. So that was really where we got a lot of information...I wouldn't want it to go on the record that there was no one who had a good luck story.*

The great disparity in the participants' experiences was understood by one as being bound up in the lack of system protocol for the treatment of mental illness, similar to the treatment of physical illness. One participant explained...

*There's no clearly systematized protocol, um, to actually, you know, go towards health...a lot of the time it's just toward controlling things that are either going to be destructive to society or destructive to themselves and it seems to sort of stop there.*

Another participant then raised the issue of mental health triage and the common misperception that they are only to be used in crisis. She felt that they are an initial point of contact for anyone with a mental health concern for themselves or a loved one, and is dismayed that so few carers know about this. Another participant felt that the problem with many mental health services is that they do not have adequate resources to perform their service. She would like to see services properly resourced before they are promoted to more people.

One participant thought it fantastic that the University of Canberra now has a free drop in centre, which allows people to explore and investigate concerns that they may have for themselves or for others. She thought that this demonstrates just how large a problem mental illness is for the ACT community, but was happy that the problem is starting to be addressed.

### **1.2.3 Internet**

The participants did report using the Internet to access mental health information; however, it was unclear whether the Internet had managed to meet their health and wellbeing information needs.

One participant explained that she uses the Internet because it is one of the most effective ways to tap into the more recent information available on mental health that may not be available from other sources.

*This is part of the problem that I've touched on before that we're in an area that's still very, very experimental and very, very dependent on the individual client. So that makes it extremely difficult to get [information]. Personally I use the Internet. I've got a couple of really good, reputable sites.*

The participants said that they use the following sites for useful and trustworthy mental health information: Blackdog, National Institute of Health, Sane, Beyond Blue, and the psychiatric page of MedScape. The participants liked these sites as they are all reliable, reputable and include journal articles, which contain information about recent findings and new trials.

When asked about checking the reliability of websites, one participant said that if she is using the Internet to find local services, she checks out the website and then calls the organisation or goes along to one of their meetings. She also uses the Internet to do general research about mental health and says that checking for reliability is more about Internet literacy than it is health literacy.

Another participant said that her preference is to not use the Internet for mental health information because there is too much "garbage" that would need to be sifted through.

#### **1.2.4 Mass Media**

The participants all agreed that mass media plays an important role in the dissemination of information about mental health and the reduction of stigma that would result from a well-educated population. The participants had different ideas about the success to date of public mental health awareness campaigns.

"I think it's too rosy," was the opinion of one participant who gave the example of a television campaign, which depicted a young woman with a mental illness working in a shop. This ad was trying to demonstrate that people with mental health issues can still lead typical lives, however, this is often not the case and many of the participants wanted that fact to be known. They acknowledged that many employers do not want the difficulty that an employee with mental health issues may present, and furthermore, that the pressures of work, particularly full-time work can trigger episodes of mental illness.

Another participant felt that community education focusses too much on mental health and not enough on mental illness. She illustrated her point with the following anecdote:

*A few years ago there was a big sign in Melbourne, and there was a big picture of Merv the cricketer...and it said 'take care of your mental health, go fishing'...and*

*[my son] said 'you should've got up there mum and written underneath: Can't, the fish talk to me'.*

She felt that campaigns such as these are about lifestyle hiccups, not the kind of mental health issues that are an impediment to choice and independent living. "That's one of the hardest things to get through to people: They would if they could." Most of the participants agreed that there is ample information in the public arena about anxiety or depressive disorders, but much less about other, and more severe, mental health issues.

### **1.2.5 Paper Based Publications**

Paper based publications were as important to the participants as any other information source. Books, newspapers and scholarly journals are used by some, if not all, of the participants; although the discussion centred around pamphlets in particular.

Pamphlets were a popular source of information for these women for a variety of reasons. For one participant the value of pamphlets lay in the author being instantly identifiable. For a couple of others it was that pamphlets are a very valuable starting point for education, as an intermediary between not knowing anything about a particular issue and going in search of more comprehensive or personalised information. For a fourth participant, pamphlets are small and concrete pieces of information that people can take away with them whether they need it at that moment or not. Several of the participants especially liked that pamphlets are often created locally and provide information about local services, organisations and support.

### **1.2.6 Family Members and Friends**

Family members and friends were not particularly useful sources of mental health information for the participants; rather, the participants found that they themselves were the source of information on mental health for their family members and friends. This was not to say that informal networks were not sources of information, but that it was often peers in mental health carer networks, rather than friends and family members.

Most of the participants agreed that they obtain a lot of information from their peers in the mental health carer community. One participant went so far as to say that she only obtains information from the people she associates with at carer forums. Another participant said that Mental Illness Education ACT was extremely important for her, because not only do they have a great deal of information available, they also provide the opportunity to meet people in a similar situation.

In terms of family members and friends, the participants all agreed that not only do they not obtain information from them, but they do not share information with them either. One participant said that it is so tiring to go to carers meetings, training courses, to be dealing with mental health professionals, and to be confronting the issues all the time, that when she is with friends she wants to relax and focus on other things. For other participants, they do not talk with



their family members and friends as they often know very little about the issues and very rarely ask about the client or the situation. One participant said that “you don’t want people to know because of the judgment.” To which another agreed, “the stigma thing is huge, you’re very careful about who you can confide in.”

The third major issue on this topic for the participants was that they are more often than not the information source for their friends and family members, and that this can be exhausting.

*I became the source...it became quite oppressive for me because I had to go out and get all the information, come back, not only deal with the client, deal with myself and then deal with my whole family, and then, you know, deal with the widening circle. I became the educative source.*

All of the participants agreed that they find themselves in an educative role for others. They said that quite often when others find themselves in a similar situation they will go directly to them for information, which can be terribly demanding.

Overall the information sharing balance, whether with peers or family members or friends, is a delicate one and each participant had their own thoughts on where this balance lay. One participant had the view that despite its bad points, a lot of information can be gained through sharing information with others. In response to this, another participant added ...

*Yes, I would...both give and get information from people that I knew had similar experiences, but outside of that I probably don't. And family I don't because, I tried earlier on, and they're good, but they've got their own...families and things and I just feel it's not fair to involve them.*

And a third added...

*There's still is a delicate balance between the whole keeping the confidentiality of my family too, you know. I find that really a delicate thing because you have this thing where...you want to speak out, you want people to be educated, but... you're talking about your own kids...You have to be that protective shell so that they actually have a space in which they can heal.*

### **1.2.7 Other Sources**

Self-help courses were raised by one participant who commented that when seeking information she attended many courses, one of which was ‘Stepping Stones’, which had a very disintegrating effect on her and reduced her ability to care. It incapacitated her, making her feel that she was the one with the mental illness. She explained that courses need to come with some sort of warning about the content that recognised the fragility of carers.

# DISCUSSION

---

Mental health carers have particular information needs that are difficult to meet; requiring the carer to look at many sources regularly in order to find new or updated information.

A significant issue for the participants was that when they first took on the caring role they needed an information source, preferably a health professional, to pre-empt their information needs. They experienced difficulty accessing information in the initial stages and said that they did not know which health professionals could inform them of the breadth of options for treating mental health issues. One participant described the feeling of walking around in a daze, and needing someone to provide the information that she did not know she was looking for.

Another issue was that while there is a great deal of information and services available, individuals may lack the time or the capacity to locate and assess the information. This is especially difficult for women to whom the responsibility for information seeking usually falls. Several participants felt that ACT needs an independent third party who indexes all mental health services, including alternative therapists and treatments. This would be a one-stop shop of information provision to mental health consumers and carers, which could personalise information within an ACT specific context. They cautioned that there are currently services that purport to be one-stop shops, but which are neither credible nor comprehensive.

## **Barriers**

Two common and significant barriers to mental health carers obtaining health and wellbeing information became apparent throughout the focus group. The first is the practice of being kept out of the loop by mental health professionals. The second is that many care recipients do not agree that they require care, which means that mental health carers must keep their search for information and membership to organisations like Carers ACT inconspicuous. These two barriers compound to make the quest for health and wellbeing information an incredibly challenging one for mental health carers.

Cost was the third most significant barrier for the participants. One participant said that every second year she attends the Australasian Schizophrenia Conference in order to obtain the latest information. She acknowledged, however, that many would not be able to afford to seek information in this way. This demonstrates the lengths that mental health carers go to in order to obtain the information they require, but also demonstrates the gap between what information can be obtained when carers have sufficient financial resources. This was reinforced by one participant who said that although she had received good advice, the services she was referred to were not covered by Medicare and therefore inaccessible for her. She and the other participants agreed that “there is a dynamic tension between getting the help you want and being able to pay for it.”

The fact that policies designed to alleviate the stress on mental health carers are not put into place in practice is also a considerable barrier in the pursuit of information for the participants. There was confusion for some of the participants around confidentiality legislation. One participant felt that the legislation makes it difficult for health professionals to pass information on to carers, but another explained that...

*Health workers hide behind the legislation. Health professionals are notorious for hiding behind the confidentiality issue. There are ways that they can provide carers with information and this information can at times be critical in the way you go about caring for a person. It is the lack of training, lack of skills and sometimes the laziness that causes this.*

She explained that many of the barriers identified by the participants and the solutions they proposed are already in the policies, but that the policies are not put into practice. The *Adversity to Advocacy*<sup>3</sup> report also found that mental health carers felt that mental health professionals and workers “often use the ‘privacy and confidentiality’ as an excuse to exclude them from the care of the person they care for.” The report continued that “privacy and confidentiality are also used as excuses to prevent information sharing between services.”

### **Gaps**

Some of the participants reflected that comprehensive information about mental illness is difficult to obtain. For example, two participants spoke about the risk of people with mental health issues becoming embroiled in sub-cultures because of the enormous difficulties they have finding and keeping friends, particularly after hospitalisation. Information of this nature is rarely available until it is experienced and shared by peers in similar circumstances.

Another gap identified, both in this and other focus groups, is that public awareness campaigns do not highlight the commonality of mental health issues, or their episodic nature. One participant highlighted that other health issues that have had great stigma associated with them—such as cancer, sexual transmitted infections, and HIV/AIDS—have come to be accepted, or more widely and accurately understood by the community. Incorporating health issues into popular culture narratives helps to dispel myths and increase awareness.

The participants agreed that it is also beneficial when public figures talk about their own experiences with mental health issues, however, they felt that commonly only depressive illnesses are publicly disclosed, whereas no public figure has spoken about other illnesses such as schizophrenia.

### **Needs**

In the wider research, ACT women highlighted the need for access to wellbeing information, not just medical information. They felt that information provision about health and wellbeing services

---

<sup>3</sup> *Op cit*, p. 66.

within the ACT was too focused on medical- or clinical-oriented services. Women, including mental health carers, need and want to know about other services, especially information provision services, such as those run through community organisations or those offered via the Internet.

The Internet is a tool of growing importance in health and wellbeing information attainment, not only because women can find information about illnesses and treatments, but also because they can create and sustain online communities where experiences and information are shared. The Internet offers enormous potential to mental health carers in this way because it can enable them to share information about local services and connect with peers without the rigidity of a physical meeting place and time.

Online peer support is seen as an appropriate model for ACT women mental health carers because it is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful<sup>4</sup> and is likely to address the barriers for women mental health carers have and that contribute to their social isolation because of stigma and lack of access to appropriate and consistent information and support. Women are likely to benefit from the online peer support as it does not utilise a medical framework, and focuses instead on building relationships that are based on support and learning and growth, and on systemic evolution as opposed to individual recovery from a specified illness.

### **Health and Mental Health Literacy**

The *It Goes with the Territory!* report highlighted the significance of good health literacy in enabling women to navigate health and wellbeing information sources; assess the usefulness and trustworthiness of the information they obtain; and understand how to apply the information where necessary and appropriate.<sup>5,6</sup>

However, the findings of the mental health carers' focus group discussion highlight that mental health literacy is an equally important, but altogether different concept. Mental health literacy includes the ability to recognise specific mental health issues; knowledge of how to seek mental health information; knowledge of risk factors and causes; knowledge of treatments and professional help available; and attitudes that promote recognition and appropriate help-seeking.

The mental health carers who participated in the discussion demonstrated a very high level of mental health literacy, but their ability to fulfil their caring role can be and often is hindered by a

---

4 Mead, S., *Defining Peer Support*, 2003, available at: <http://www.mentalhealthpeers.com/booksarticles.html>

5 Torres, R. & Marks, R., "Relationships Among Health Literacy, Knowledge About Hormone Therapy, Self Efficacy and Decision Making Among Postmenopausal Health." *Journal of Health Communication*, 2009, 14(1), pp.43–55.

6 von Wagner, C., Knight, K., Steptoe, A. & Wardle, J., "Functional health literacy and health promoting behaviour in a national sample of British adults", *Journal of Epidemiology and Community Health*, 2007, 61(12), pp. 1086–1090.

poor level of mental health literacy in the community and among health professionals. Alongside campaigns to improve community *health literacy* there needs to be campaigns to improve community *mental health literacy*. This improvement will aid in tackling the high level of stigma associated with mental health issues caused by misunderstanding, stereotyping and fear. Such an improvement would also increase community awareness of and appreciation for the role of mental health carers and enable them to more easily access the information they need.

# CONCLUSION

---

This report demonstrates that women mental health carers face a number of barriers to accessing the health and wellbeing information they need, which include, but are not limited to: being shut off from information and knowledge by mental health professionals and workers; not being respected in their role by mental health professionals and workers; being denied information on the premise of confidentiality and privacy; not having a central source of ACT specific information on mental health treatments and services; and not being able to afford many of the options that do exist.

Mental health carers are also greatly affected by the level of discrimination and stigma that exists around mental illness in the community, which can be very isolating and curb their function as carers.

Mental health carers have to consistently seek information and constantly reassess that information in light of new or conflicting information. “The system is luck,” as one participant pointed out. This comment is significant, because as previous comments have recognised, there are no clear channels of mental health information that participants felt are reliable, trustworthy and constant.

Women who are mental health carers need access to up-to-date and relevant information from trusted sources. This means that local and trusted health and wellbeing information sources need to be promoted over time to be visible and accessible to them. Ensuring that mental health carers can access the health and wellbeing information they require will enable them to fulfil their caring role and assist in their health decision-making.

But more than this, community attitudes towards and knowledge of mental health issues need to be addressed through public education campaigns because this too will increase the ease with which mental health carers can fulfil their role.

# REFERENCES

---

Mead, S., *Defining Peer Support*, 2003.

Available at: <http://www.mentalhealthpeers.com/booksarticles.html>

Mental Health Council of Australia, *Adversity to Advocacy: The Lives and Hopes of Mental Health Carers*, Mental Health Council of Australia; Canberra, 2009.

Murphy, M., Murphy, B. & Kanost, D., *Access the Women's Health Information: A Literature Review of Women as Information Seekers*, Women's Health Victoria; Melbourne, 2003.

Torres, R. & Marks, R., "Relationships Among Health Literacy, Knowledge About Hormone Therapy, Self Efficacy and Decision Making Among Postmenopausal Health", *Journal of Health Communication*, 14(1), 2009.

von Wagner, C., Knight, K., Steptoe, A. & Wardle, J., "Functional health literacy and health promoting behaviour in a national sample of British adults", *Journal of Epidemiology and Community Health*, 61(12), 2007.

