

MHCA Mental Health Carers Engagement Project

Focus Group Report

1. Introduction

On 8 October 2007, the Mental Health Council of Australia (MHCA) held a carers focus group meeting to assist with the development of content for workshops to be held for mental health carers nationally. Further information about the workshops and the project can be found at Attachment A.

Twenty-eight mental health carers from across Australia, with varying lengths of time caring for someone with a mental illness and multiple variations of who that person is were included in this meeting. Participants included carers from rural and remote areas, as well as Indigenous and Culturally & Linguistically Diverse (CALD) carers as these groups will be specifically targeted in the MHCA Carers Engagement Project.

MHCA gratefully acknowledges the input of all of the carers who gave up their time to attend this meeting and provided their input and expertise.

This document is a record of the issues discussed at the meeting as participants requested access to the information they and others shared at the meeting.

The meeting agenda is at Attachment B. One aspect of the meeting was to find out what the experiences were for carers, while another aspect was to trial whether some of the methods used at the focus group meeting would be effective in workshops throughout the country. In hindsight, this was too much to do in one day and some of the evaluation comments reflect participants' frustration that sessions were cut short or not covered due to time constraints. The notes below only reflect the sessions that were covered.

Immediately prior to the meeting, Senator Nigel Scullion, Minister for Community Services, launched the Carers Engagement Project as one of a number of carer initiatives funded by the Australian Government Department of Families, Community Services and Indigenous Affairs (FACSIA).

2. Carers' experiences of care

In the first session, carers were asked about their experiences of being a carer. The aim of this session was to get a sense of the shared experiences of mental health caring and to give carers the opportunity to hear from others what their key issues were. They provided written and verbal input in the following areas.

2.1 Experiences of mental health services and service providers

Carers reported health care providers and mental health services inadequately met their needs and that it was often difficult to access appropriate services:

- Confusion who to ask for help
- Not being heard
- Getting others to believe me
- No care for the carer, or little
- Lack of consistent help and service delivery

- Determination, determination, determination against the odds - not being heard
- Not being understood
- Respect as a carer by service provider
- I manage [my relationship with the] mental health service effectively
- Inability to understand need or consumer
- Lack of service provision
- Clinicians not listening
- Clinicians not giving me guidance how to manage my ill relative
- Remoteness [of us in relation to service providers]
- Isolation
- Move to city for services away from support
- Difficulty accessing psych services in rural areas
- Language difficulties
- Lack of interpreters
- Not understanding cultures
- The search for answers and understanding
- Scared that the clinicians are not going to (again) respond in time of crisis
- Multiple ECTs¹ being administered with no improvement despite my objection
- Power. Abused by health care workers. ie. use their knowledge/power to put us down.
- Lack of respect
- Gain new support from NGO mental health
- Become a voice for those whom are unheard
- Feelings of rejection by mental health professionals
- The system. Coldness, clinical approach
- Discussions around the delicacy of dealing with disorders – both diagnosed and undiagnosed – and how one deals with the competing needs of privacy/respect and communication/education/assertion of needs
- Becoming an effective educator to clinicians (despite power imbalance)
- Acknowledgment of carer's contribution to consumer's wellbeing
- Information on who can help
- Frustration looking into services and referrals, can seem ongoing
- Lack of initial information on diagnoses on how to 'care' and where to go for help x 2
- 'Manhandling' the issues of confidentiality
- Lack of information
- Being unheard, being invisible
- Frustration with medical providers and hospital system
- Long waiting times in emergency at the hospital. Four hours waiting with a psychotic relative is very distressing
- My opinion listened to but not acted upon by doctors and medical people. Told I am too emotionally involved
- Initially on onset of illness, little notice taken of my cries for help from [the mental health service]
- Not enough support for my family at hospital admissions level in early days either during the first experience or any following admissions.
- The confusion and isolation at the time of diagnoses and lack of information about where to turn for help
- Disempowerment, isolation, custodial issues
- [Difficulty in knowing] how to manage police efficiently

¹ Electroconvulsive Therapy

- Being ignored and treated with disrespect
- Services provided do not consider carer input (we are the daily expert)
- Frustration and hopelessness at times with lack of facilities and room at hospital level
- Recovery seems to exclude carers as it is misinterpreted by service providers as client focussed
- Ongoing services for [the person I care for] with high level needs have been discontinued except for faxing of regular prescription to chemist
- Physical health of [the person I care for] are ignored
- [The person I care for] lack of self care due to the symptoms of schizophrenia is interpreted by psychiatrist as a life style choice
- Inconsistency of services can be both confusing and demoralising. Crisis teams respond differently in different areas and consumers move frequently
- Guardedness of many health professionals especially psychiatrists. Let you do all the unpaid work and tell you nothing. They don't ever answer letters
- Confidentiality clause still being too rigidly adhered to in many cases. The people who need to know (the carers) are being starved of vital information
- The assumptions made by some service professionals are that you will always pick up the pieces. They don't know or care about your circumstances
- Area mental health services in [my state] can create artificial barriers to consistent care if the consumer moves from one area to another
- Failure to be recognised as a legitimate spokesperson by services in relation to [the person I care for] illness.

2.2 Emotional and mental experiences of caring

Mental health carers reported a range of mental and emotional feelings in relation to their caring experiences – from highly positive to very negative:

- Shame of identifying nature of illness
- Enduring, unending grief
- MAD (at myself)
- Wanting to die but having to live
- Not Supported
- Abandonment/lack of support, no one wants to know
- Alienation from community
- FEAR
- Fear of the present and the future
- Stigma
- Causes depression of the carer
- Blame and guilty as a mother
- Frustration with person not willing to take responsibility for their behaviour which is affecting so many others
- Resentment
- Frustration with person affected as he won't admit he is unwell
- Anger from partner when I am trying to help
- Fear of not understanding illness
- Need for solid support
- Immensely sad
- Feelings of being alone
- Exhausted
- Tired
- Shocked

- Stressed
- Judged
- Afraid
- Developing a sense of self and empowerment against the odds
- Resilient
- Supported
- No support provided, aggression from loved one
- Life experience, growth from exposure as a whole (or by individuals close to them)
- A sense of anger that beauty is vary rarely acknowledged or accepted by society
- Acceptance. Accepting the situation and learning how to deal with it yourself as well as the world around you not looking down on it.
- Learning about mental illness occurs through crisis and personal experience
- Learnt to say no
- Become strong person
- Learnt to object
- Ability to swallow pride
- Anxiety/concern
- Desperation
- Carers are important to the well being of the health of the person
- Feelings of isolation, loss, guilt, grieving and depression
- Emotionally draining
- Coping. I cope when my child is coping, but it is harder to stay focussed when my child is unwell
- Ability to cope in any situation
- An immensely much greater appreciation of the “Beauty” within the Body (brain) of the person who is ill
- Has made me a ‘better person’ (I believe at least more compassionate and more understanding of others)
- Guilt. Of feeling tired and selfish
- Stigma is such a stigmatising word – but what does one do about the relentlessness of the stigma attached
- Stigma of mental illness x 2
- Dealing with anxiety
- Dealing with the knowledge of genetic inheritance
- Dealing with losses in relationships
- Grief x 2
- Isolation caused by stigma associated with mental illness x 2
- Isolation and fear x 3
- Emotionally stretched
- Frustration of the situation as a result of my loved ones illness
- Complete feeling of isolation from usual social network
- Confusion x 2
- Trying to stay one step ahead in regard to relapse, hypervigilance
- Lack of confidence that we as a family are providing appropriate support
- Denial, blame, judgment
- Grief and loss, and adjusting to difficult expectations
- Anxiety about my capacity to cope with the impact of episodes
- Lack of patience
- Being with and being the target of extreme anger, frustration and pain

- Guilt
- Anxiety that my grandchildren may suffer from their parents illness
- Damned if you do.....damned if you don't
- Frustration x 4
- Learning to congratulate myself on the efforts I've made in the wider mental health field
- Dealing with my personal grief through counselling
- Learning new skills and gaining new gratifications
- Suppressing my needs
- Missing years
- Trying to find balance, nurture self – have own life
- Shock, trauma, violence, wild ups and downs
- Frustration at trying to change the system
- The daily/weekly/monthly/yearly activity of a carer for a mentally ill family member
- The relief of becoming involved with people who are on the same journey.

2.3 Experiences relating to education and advocacy

Many carers have used their personal experiences to go on to educate others about mental illness:

- Lack of knowledge/ information
- Knowledge is essential. ie courses like [a local course] empower us and give us strength
- Education – access to info and support services
- Who and how do the education needs for general social awareness get addressed – particularly for other sections of families/work/other networks – because support only ever works if it does form a net
- Lack of public education. Having to deal with negative perception and uninformed people
- Awareness of the multiplicity of disorders/ caring challenges encountered in big families e.g. only one out of our family of eight has NOT had a mental health episode
- The terror of using the skills I have to empower and help other carers develop (advocacy)
- Addressing public forums – speaking clearly about mental illness issues
- Engaging an audience when speaking of our family's pain
- Relentless advocacy, campaign strategy.

2.4 Physical experiences of caring

This is addressed further in section 3 of this report:

- Full time care (24 x 7)
- Encouraging daily living skills for our loved ones
- My health went to crisis point and I ended up in ICU
- Dealing with sleeplessness x 2
- Fatigue x 3.

2.5 Financial experiences of caring

Carers often experience an enormous impact on their finances or ability to earn due to the time and unpredictability of caring for a person with mental illness:

- Financial disadvantage
- Employment restrictions due to Centrelink cut off to keep health care card for subsidised medicine
- Worked on and off between when my partner's illness is stable

- Lack of financial support for carers coming from rural areas to care for consumers
- Financially stretched x 2
- Education for budgeting for the mentally unwell when they are recovering – there seems to be big gaps between financial management orders and any form of gradual support for clients
- Financial worries because my wife could not work anymore and I gave up work to care for her for several years
- Need recognition from government, employers and communities that I have additional and often vital care responsibilities
- Financial problems
- Financial drain due to physical illness as well as needing counselling
- Financial hardship arising from the losses through [the person I care for] making unwise business decisions, risk taking and gambling
- No financial support for grandparents caring for children of a patient
- We lost our family home and future [due to caring]. We have no financial security, and now rent a house after 25years of ownership
- Fear for the future as the impact of broken employment bites and resources are eroded
- At age 54 and 51, we are scared about our future. The future we planned for is gone forever now no matter what we do.

2.6 Social impact of caring

Carers are immensely impacted upon by how society views mental illness. While there were a few positive social experiences from caring, most participants reported negative experiences:

- Loss of future for we parents as well as our unwell son
- Lack of community understanding of what the life of a carer is
- Lack of support for families
- Lack of understanding from others
- Dealing with children's reactions to father's behaviour, sadness helplessness.
- I had to make changes to how I was to spend my time in retirement
- Neglect of other members of family
- Lack of education
- Understanding and support, guidance and encouragement from [mental health organisation]
- Relief at finding a safe place to talk - [mental health organisation]
- Resilience needed: speaking out on individual level, local level and systemic level
- Change of lifetime in retirement
- Stigma
- Social isolation, family disruption
- Isolation. I am not the only one/there are people all around me
- Affects other relationships in the family often negatively
- Communication.
- Someone who you can talk to and accepts the warts and all situation. Doesn't judge, just listens.
- Support network. Mental health carers/case workers, family and friends is essential
- Helped children gain a voice to be heard
- Having a strong family unit is vital
- Ability to become a strong family unit
- Rebuilding relationships from a positive base

- Educating family, friends and colleagues about mental illness
- Meeting new people
- Developing community networks
- Need time for myself to be normal. i.e. coffee with friends
- The community don't want to know carers plight when it comes to mental illness
- Lack of knowledge about mental illness.

2.7 Feedback on value of this session

This session was a combination of individuals writing their experiences on sticky notes and then pasting these onto larger pieces of paper under particular headings and talking about the similarities and differences in small groups. Each small group then reported back to the whole group.

Participants were asked if the processes used in this session allowed them to voice their personal experiences and needs as a carer. Thirteen of the 28 respondents agreed with this question, 14 somewhat agreed and one respondent disagreed.

This indicates the participants value the opportunity to talk with other carers about what it is like being a carer.

Participants were asked what should be added to the process to make it more effective:

- More time to discuss issues
- A smaller group – difficult for all to have their say within a large group
- Need to define aims of the workshops more clearly
- Redo the exercise after listening to each group
- Different focus on different ages, carer experiences, cultures, etc
- A clearer understanding of what's being sought.

They were also asked what should be removed from the process to make it more effective:

- Individuals sharing experiences should have been discussed prior to this process as everyone's needs were similar
- Try to stop some people talking too much
- Focus on particular themes
- Separate the concept of brainstorming from learning
- The sticky notes – working out how to prioritise them caused confusion in the group
- Giant pieces of paper were annoying to use.

MHCA staff will need some way of taking information from workshops away with them (to use in the reporting) and while the sticky notes gave each individual the opportunity to write their own notes and add it to a larger poster, it appears that parts of this process, such as also prioritising them, was not appropriate to continue in subsequent workshops.

3. The health impacts of caring and methods for managing

3.1 Health impacts of caring

As part of agenda item one 'carers needs', carers at the meeting were asked how caring impacts on their health. They provided the following answers. Some of these cross over with what carers reported were their experiences of being a carer – highlighting the enormous impact caring obviously has on their health.

3.1.1 Impact of caring on physical health

Carers' physical health was severely impacted on by their caring role:

- Anxiety worsens my asthma – acute allergic reactions
- Makes me eat and drink too much
- Caring has contributed greatly to my husband's bowel disorder/stress
- Detrimental effect on sex life/libido x 3
- No time to think of your own health
- Sadness, depression x 2
- Don't have time to think
- Smoke for longer than I may have
- Increased smoking x 2
- Eating your emotions/ weight problems x 3
- Constrains social life, bizarre behaviour of person with mental illness means don't invite new friends over
- High blood pressure x 2
- Time poor, so consequently making mistakes by rushing
- Wearing, exhausting, disempowering, ageing, neglect of self and own needs
- Disruption of daily life and living patterns and cycles
- Low energy levels
- Compromised immune system due to long term stress, unpredictability of illness
- Irreversible damage to my heart living with constant adrenalin
- Nightmares and horrific dreams
- Illness - hypertension, lowering of resistance
- Not eating properly. No interest in food
- Fragility. Crying easily, effected by the simplest situation
- I look for comfort food
- Chronic hives
- Diabetes from not being able to look after myself
- Breast cancer from stress
- High blood pressure x 4
- Pain [various reported due to tension]
- Fragmented sleep
- Inability to always sleep soundly
- Lack of sleep
- Tiredness/ lack of sleep
- Sleeplessness, effect on relationships
- Physical health complaints x3
- Emotional eating, over or under eating,
- Alcohol abuse
- Chronic hard to manage health conditions can arise long term
- Irritable bowel syndrome
- Stress headaches
- Initially lost 20kg in short space of time. Couldn't eat
- Passive smoking in mental health units impacts on my health
- Lethargic
- Lack of exercise
- Nightmares, sleep problems, fatigue x 2
- Downgrade importance of looking after yourself
- No time to look after myself x 5.

3.1.2 Impact of caring on emotional and mental health

Carers at this meeting reported that their emotional and mental health was affected by caring, which is consistent with a number of research findings on carers' experiences:

- Guilt x 3
- Despair
- Disempowerment
- Frustration x 2
- Anger x 2
- Grief x 2
- Grief about your and love ones situation x 2
- Numb
- Over expressive
- Negative impact on relationships causes emotional problems x 2
- Guilt over being the possible cause of the illness (i.e. failure to know about the risks associated with [the person I care for] using cannabis)
- Anxiety x 2
- Stress and anxiety x 5
- Creates anxiety and stress, depression x4
- Feeling overwhelmed x 2
- Fatigue x 2
- Exhaustion
- Reduced frustration tolerance
- Increased isolation
- Concern for children's wellbeing
- Reduced objectivity
- Increased emotionality
- Stress x 3
- Broken heart
- Emotional void
- Lack of control of emotions – anger, frustration, sometimes emotional disconnection
- Silence, no talking, what is the point?
- Social isolation, did not want to mix with friends or the world
- Loss of interest in mundane things like house maintenance
- Grief over the loss of the loved one as we know them
- Inability to cope as well as previously.
- People just assumed I was very strong
- Trauma of dealing with children's loss of father/ his anger etc
- Demoralised
- Holistic approach – less capacity to cope
- Impact on marriage
- Impact of grief which has no acknowledgement in our community
- Compassion x 2
- Insomnia
- Relationship conflict
- Chaotic lifestyle
- Regenerates my own previous life childhood trauma
- Lack of support
- Depression, 'contagious' depression
- Post-traumatic stress

- Mentally reduced capacity to focus
- Wonder if I would have these problems anyway or are they because I am a carer? Do I blame it unfairly on the person with mental illness?
- Took it personally. It was my fault. Looked and searched for a reason.

3.1.3 Impact of caring on spiritual health

Some carers separated the impact caring has on them from a spiritual perspective:

- Lack of sense of peace and contentment
- Anxiety corrected with prayer and bible reading
- Isolation from family and friends
- Growth as a more compassionate person
- Growth x 2
- Spiritual growth – a better person.

3.2 Carers' methods for managing stress and impact on emotional and mental health

The experiences and impacts of caring strongly highlighted the toll caring takes on mental health carers' own mental and emotional wellbeing. This session focussed on methods for managing these impacts and carers at the meeting offered their own stress management methods.

3.2.1 Methods that help carers to feel emotionally and mentally supported

Carers valued formal and professional support but most utilised less formal support mechanisms. Many also reported support mechanisms that relied on their own resilience:

- Someone who knows to walk beside you as a friend. Keep looking for kindred spirits
- Finding someone who truly understands
- Supporting and being supported by other carers
- Debriefing with understanding friends and family members
- Debrief with other carers
- Talking through scenarios, problem solving
- Limit the time talking about mental illness to ½ hour a day unless there is a crisis
- Talking out your problems
- Taking responsibility for own health x2
- Sharing the load with family and friends
- Talking to Carers' Associations – others in similar situations
- Going home – being back on my land with family and kin
- Focus on my family – are they OK?
- Recognising positive changes
- Looking for strengths rather than weaknesses
- Taking an assertive approach to challenges
- Being optimistic
- Maintain a positive attitude
- Good positive attitude x2
- Remember happy times
- Creating boundaries x2
- Set boundaries around time, space and expectations
- Good boundaries
- Time out
- Respite x2
- Counselling x4
- Peer group support

- Self validation
- Develop role other than that of carer – avoid being engulfed by it
- Keep mentally alert
- Have the attitude that you also have a right to life and things you enjoy
- Compartmentalise parts of my life and keep caring separate
- Maintaining an independent lifestyle
- Looking at the big picture, having a future plan
- Accepting a family member's illness and being able to relate to them
- Accept person has mental illness and then move on
- Seeking clinical help in a timely manner
- Winding the windows up in the car and screaming.

3.2.2 Physical or mental activities to assist with stress management

Participants had many activities or approaches they used for dealing with the stress of caring:

- Singing and dancing
- Choral singing is great for all aspects of health
- Sing
- Dance
- My music is my escape
- A structured social life that provides relaxation, company, stimulation and connectedness
- Bushwalking in a group is great, recharges the batteries, provides relaxing company
- Walking
- Sport
- Exercise x4
- Run
- Jog
- Tennis
- Walk
- The gym
- Pilates each week and playing bad golf
- Learning a language is engrossing, it helps to tune you out
- Reading x2
- Laughter x2
- Doing something nice for yourself
- Developing a hobby
- Creative outlets such as reading, painting, drawing x2
- Gardening x2
- Trying to grow roses
- Taking holidays, taking time out from the carer role
- Watch crap TV x2
- Sex x2
- Maintaining positive routines
- Good diet and exercise, going to the gym
- Good diet
- Listening to music x2
- Going to concerts x2
- Animals, pets
- Volunteering

- A new job
- Creativity
- Making something from scratch
- Activities to occupy the mind
- Smoking
- Alcohol
- Swearing
- Knitting.

3.2.4 Education or advocacy as a method for managing stress

As in section 2.3, many carers did education or advocacy activities to assist in managing stress:

- Being a facilitator for [a mental health carers course] has helped me by helping others
- Working harder in advocacy x3
- Being included in planning by clinicians
- Increasing knowledge and understanding
- Self educating and educating others x4
- “Helping to vote out Howard Govt.”

3.2.5 Spiritual methods for managing stress

While fewer participants listed that caring impacted on their spiritual health (section 3.1.3), many had spiritual methods for managing stress or nurturing themselves:

- I practice giving and receiving light and spiritual teachings such as gratitude, humility and acceptance
- Spiritual comfort, support through the bible
- Prayer x2
- Meditation x6
- Meditation – losing yourself
- Reflection, silent time. The world is a great place and I am lucky to be a part of it
- Contemplation
- Relaxation exercises x4
- Seek out a spiritual purpose
- Spiritual activities
- Leave space for spiritual communication
- Be grateful that I get up breathing
- Pursue my many interests for myself and to lead by example
- Being patient with myself and realising how much food helps
- I cry a lot
- Expect less of myself
- Love more
- Sense of humour
- Talking to the flowers
- Having the telephone off, or not always answering it
- Achieving something to prove you are still a worthwhile person
- Limiting life to a simple and safe routine I could cope with.

3.3 Feedback on value of this session

This session was a combination of individuals writing their experiences on sticky notes and then pasting these onto larger pieces of paper under particular headings and talking about the

methods as a whole group. It was designed to give participants a chance to hear more about how other carers manage stress and anxiety and also share their own expertise with others.

Participants were asked if the information was presented in a way that would enable them to make positive changes in caring for their own health and wellbeing. Seventeen of the 28 respondents somewhat agreed that it would, but eight disagreed and considered it would not. Three respondents did not comment.

Due to time constraints, this section of the workshop was only minimally covered. Some information was provided to the group regarding stress and recovery. Group discussion was held regarding what would be an effective session on carer health in a one-day workshop. The facilitator sought information from the group regarding what strategies they successfully employ and asked other group members if training in such strategies would work for them.

Suggestions for making this session more effective in a workshop:

- More discussion of personal experiences
- Duplicate copy of points noted to keep for own reference
- More clarity
- More on strategies
- Sharing with the group “what makes us feel good” because this is what we lose touch with as carers
- Letting other’s know what has worked for you
- Present to people in rural/regional areas
- Results recorded on a whiteboard would avoid repetition
- Clearer objectives needed
- Little information presented
- Facilitator needs to be careful to let everyone have a say
- Not being heard or being unable to get point across
- The same people encouraged to comment, making it difficult for others to speak
- Provide tools and space to give ‘permission’ for self care rather than go through all the methods of caring for self.
- Reframe ‘selfishness’ – many carers believe it is selfish to care for their own health.
- Elicit individual strategies for self care and reinforce implementation of these strategies, eg with permission to do so, and with information re consequences of not caring for self.

4. Carers’ information needs

Carers were asked what information they needed to better support or inform them in mental health caring and making decisions on behalf of the person they cared for. A key point raised by the group was that this can be very different depending where on the caring journey the carer is. Some said they were overwhelmed with information upon diagnosis for the person they cared for and they had little knowledge on how to filter what was good or valuable information and what was not. However, many considered there was more often a lack of information, not too much.

4.1 Information needs of carers

Participants were asked what was the ‘must have’ information for new carers:

- How to self care
- How to advocate
- Available services for carers AND consumers

- Monetary assistance
- Centrelink requirements
- Implications of diagnoses
- Best therapeutic approach
- Guidance on how to collaborate with clinicians
- Up to date, relevant, and accurate information on mental illness
- Information on communicating with unwell people
- Interpreting clinical information, ie. the results of brain scans

4.2 Most useful information

Participants were asked what they learnt that was most useful in their caring situation

About mental illness

- How depression affected my wife
- Impact of the illness
- Clarification of illness
- Can be difficult to accept
- Understanding how changes in behaviour happen
- Understanding that the illness is not my fault – it's an illness
- Get support for yourself and family asap
- People's reaction to mental illness, they don't know what to do
- Support from family

About medicines

- The side effects of certain drugs
- Medications don't always work and often require specific instructions to be effective (i.e. to be taken with food)
- Addictions

About service providers and health services

- Often poorly trained
- Are stressed
- Hard to access publicly funded practices.

4.3 Access to information

Participants were asked where they have sourced useful information from when they needed it.

- Through [mental health organisation]
- Through the Internet
- By turning to people with experience
- Other carers and carer-friendly clinicians
- By self focus and through counselling
- Through [mental health and carers] course
- [mental health organisation] library
- When being assertive with clinicians.

4.4 Support to use resources

Participants were asked what the most important milestones were in the information journey and what they found supported them using the information they sourced:

- Being in a good head space to support other carers as well as my own loved one

- Finding [mental health organisation] and finding someone who would listen and provide support
- Being able to meet with a psychiatrist as a family group
- Learning to ask questions
- Understanding that my illness helped me to change my attitude and have the ability to stand back
- Finding a good counsellor
- Attending and teaching the [mental health and carers] course
- Undertaking education groups.

4.5 Feedback on value of this session

This session was mainly a written exercise where participants wrote their answers to pre-prepared questions about their information needs. This was then collected by MHCA staff, and some key points from each small group were shared with the whole group.

Participants were asked if they benefitted from the group members sharing their experiences of their information needs with 19 of the 28 respondents answering yes, one respondent answered no, and eight respondents did not comment. They were also asked if they benefitted from hearing how other carers accessed the information they need. Thirteen of the 28 respondents answered yes to this question, six respondents answered no, and nine respondents did not comment.

5. Overall workshop evaluation

Participants listed the things they found most useful about the day:

- Interacting with other carers and listening informally over lunch with their insights and experiences
- Meeting other carers
- Unaware that it was 'training'
- Did not consider it as a training day, rather a brainstorming day
- Planned 'training' elements covering health and communication were not covered as information was gathered re communication in other sections and a change of approach was suggested re health. Re health – group strongly suggested and supported the concept of giving permission for carers to care for their own health was essential before anything else would be effective.
- Networking
- Very little.

Things that should be changed, added or omitted from future workshops to improve its effectiveness:

- A microphone
- Outcomes needed to be clearer
- A greater understanding of what will happen to this info (when/why)
- Have questions posted out before the workshop
- More specific questions on surveys.

Due to time constraints and allowing participants to talk with other carers as much as possible, several items from the agenda were not covered or covered only minimally. For example, a specific session on mental health service provision was not held as many issues about mental health services and health professionals came up in other discussions. Feedback indicated that it may be worthwhile including a communication session that provides carers

with very concrete communication skills eg. actual sentences, questions for carers to use in asking for information. However, this should be balanced with time constraints, which are a large factor to consider in the final workshop design

Participants were asked if they considered the trainer helpful, approachable and professional:

- Was difficult to get my contribution heard despite indication to say something
- Somewhat
- Yes, in a very difficult situation
- She was approachable and professional, carers en masse can be a challenge
- Yes, however could have been better if trainer was clearer with expectations.

General questions about the venue and catering etc were very favourably reported.

6. Conclusions

The focus group participants highly valued time spent with other carers to discuss the issues, difficulties and experiences of caring. They found it useful to hear from others and this can prompt carers to approach issues in a different way. Participants also found it useful to hear about what others do to manage the stress and health impacts of caring and feedback indicated that this information would be useful to other carers.

MHCA needs to be aware that a one-day workshop will not be able to cover all things for all carers and that where carers are in the caring journey impacts heavily on what is appropriate at any one time. MHCA should ensure that future workshop sessions include topics that would be relevant to the greatest number of participants as possible.

Useful sessions that should be included in future workshops are a session on the experiences of caring, how to deal with the impact of caring, and where to *get* good information rather than handing out information that may or may not be relevant to carers at that time.

Carers Engagement Project

The Mental Health Council of Australia (MHCA) will work with mental health carers throughout Australia in early 2008 through its Carers Engagement Project.

Aim

The aim of the Project is to:

- hear and record the real life experiences of mental health carers
- encourage carers to identify their current and future information needs
- provide a method of ongoing monitoring of carers' experiences by the MHCA

Project

MHCA will deliver workshops that will provide opportunities for family members and carers of a person with a mental illness to further develop their coping and management skills.

There will be specific workshops for carers who are Indigenous, from a culturally and linguistically diverse background, and young carers.

The Project will include 40 one-day workshops, which will provide an empowering experience where mental health carers will not only have the opportunity to share and learn but also provide the MHCA with information of relevance to advance the issue and needs of mental health carers in Australia at the national level. MHCA will use the experiences and information discussed at the workshops to advocate for better outcomes for mental health carers through the development of an annual snapshot of carers' experiences. This snapshot will be used to demonstrate over time any improvements for mental health carers as well as the areas that still need work.

In the past the MHCA has brought the issues of mental health care to national attention in such documents as the *'Out of Hospital Out of Mind'* report of 2003 and the *'Not for Service'* report 2005. (both available on the MHCA website available at <http://www.mhca.org.au>.)

Workshop Distribution

The MHCA will host twenty workshops for mental health carers in major urban areas, ten in regional centres and ten in more rural and remote settings. A minimum of four workshops will be held in each state and territory covering one of each of the above areas.

Participants

The MHCA invites mental health carers from all backgrounds and all areas. The wider the experience of participants the more diverse carer experiences will be heard and used in national advocacy to improve policy initiatives for carers.

Workshop Content

The four key aspects to the workshops include an opportunity to:

- legitimise and validate the experience of mental health carers
- identify key issues in mental health service provision from a carer perspective
- gain information about the role of mental health carers and available supports
- engage in monitoring and reporting the carer experience of service provision to individuals and families experiencing mental health issues

To discuss the possibility of the MHCA working with you or your local organisation to hold a workshop in your area or for any further information, please contact Linda Rosie, Project Manager, Carers Engagement Project tel: (02) 6285 3100, email: linda.rosie@MHCA.org.au (Monday to Wednesday).

Funding for this project is provided by the Australian Government Department of Families, Community Services and Indigenous Affairs.

October 2007



Carers Engagement Project
LAUNCH AND CARERS FOCUS GROUP
Monday, 8 October 2007

- 8.00am** **Arrival for 8.30, Breakfast available**
- 8.30am** **Launch of Project by Senator Nigel Scullion**
- 9.30am** **Focus Group – Session 1 – The Experience of Caring
and the Needs of Carers**
- 11.00am** **Morning tea**
- 11.15am** **Focus Group – Session 2 – Carers Perspectives of
Mental Health Service Provision – What Do Carers
Need?**
- 12.45pm** **Lunch**
- 1.30pm** **Focus Group – Session 3 – Information Needs for
Caring – Service Provision and the Role of Caring**
- 2.45pm** **Close of Focus Group Meeting**
Afternoon Tea
- 3.00pm** **Project Advisory Group Meeting**
- 4.00pm** **Close of Meeting**

For further information, please contact the Project Manager, Carers
Engagement Project – Telephone: (02) 6285 3100; Email:
admin@mhca.org.au

Dated: 27 September 2007