

MindLine No 11

ARAFMI Hobart: Autumn 2004

97 Campbell St Hobart 7000 Ph 62 369 251 HelpLine www.tased.edu.au/tasonline/mhcrcl

A BIG Thank You to everyone for their donations of stamp booklets for MindLine!!!

Support Meetings	Venue	Date / Topic
Hobart	97 Campbell St Hobart <u>Trade table:</u> bring small items to sell for fund raising. Some parking at rear of bldg. Followed by supper. Everyone is welcome!! February 12th 7.30pm.	Always 2nd Thursday evenings of the month usually at 7.30pm. 8th April "Raise your questions" 13th May. Malcolm speaking on his recovery. 10th June Amanda speaks about being a parent with mental illness: what works?
NEW	Day time Hobart meeting! First Wednesday of month at 10.30am til 12.00.	Special Consumer meeting: 7th April 10.30am with morning tea. 5th May " 2nd June

If you would like to receive **MindLine by email** and save ARAFMI postage & handling, please contact us ASAP!

Library Overdues:

Please remember that borrowings are for 3 weeks, so please return your materials so that other people may benefit from them: Thank you borrowers.

. If you are a permanent [Telstra Group employee](#) you can apply for a grant of up to \$1,500 to support a [not-for-profit organisation](#) or activity that a child in your [immediate family](#) is involved with.

<http://202.12.135.148/dir148/tfweb.nsf/webdocs/TK~ApplicationGuidelines?opendocument>

Alternative Counselling Service

The counsellor will be Anne and fees will apply (from \$10 per hour for people with Health Care Cards) on a graduated scale according to income. Customers will be offered a full hour consultation.

Please book by phoning 1800 808 890.

Appointments will usually be offered on Mondays Times: 10am, 11.15, 1.30, 2.45, 3.50pm

Greater partnership between consumer, family, clinicians

Presentation delivered to Mental Health Services Non-Government Forum 26/2/04 by Anne Bevan

Just a warning that this talk may suffer from a bad case of redrafting-itis...

Previously I've talked to this meeting about consumer and carer participation at the various levels that I understand: that is the National, State MHS, MHS Facility & NGOs and the Clinical levels.

Today I want to talk about carer/family participation at the clinical level, that is, between parent/partner/friend and ward nurses, case managers and psychiatrists. Real participation must start and finish here where substantial progress can be made.

Confidentiality

A major barrier to family involvement is the confidentiality issue and really I think that an overstrict interpretation can get in the way of more appropriate clinical care and thus be a barrier to the longer term health of the consumer. This is what I want to address today.

Sometimes the consumer rightly may not want a family member consulted in situations where there has been a break down in relationship or some form of abuse and I'm not talking about those situations. I'm talking about the family member who has perhaps assisted in getting the person into care and/ or who lives with that person.

Confidentiality is one value among several, other values pertinent here are the notion of the 'duty of care' and the 'need to know'. Sometimes confidentiality is decreased in response to the perceived greater need for the consumers' health needs or safety or where someone has to know certain details in order to be more effective in their responses. Workers will routinely break requests for confidentiality in cases where there is immediate suicidal intent or threatened aggression. These issues are not taken lightly by anyone and rightly so.

When it comes to so-called mental illness, the objective tests aren't really there yet and the clinician has to depend much more upon observations and collateral report of the same. Now if the clinician does not access that collateral information from significant others on the pretext of confidentiality ie that the consumer does not want them to be involved, then it can be a slower more difficult process to gain a gain clear clinical picture of what's going on. Misdiagnosis can even occur.

The issues is particularly important when the person has an undiagnosed psychosis and consequently lacks insight. Relying only on an unwell person's testimony as to their current condition may not reveal all that the clinician needs to know.

"We have all encountered people with a psychotic illness, who have become quite rational as soon as the doctor appears. This period is usually brief, but it is long enough to make an inexperienced or overworked doctor conclude that nothing is wrong if collateral evidence is excluded." (Gavin Bird Treasurer Schiz Fellowship of Sth Qld at Forensic MH address 2003).

If the family are not consulted the person may not be able to gain a much needed admission or the medication or counseling that they really need. Safety issues may not be revealed. Not consulting with key support persons is thus a barrier to both early intervention and timely treatment approaches.

Although I support every encouragement of consumers to give consent, I believe that there needs to be a balance between rights to privacy and needs or rights to being given the necessary care that will be more likely to increase a person's life chances and health. Where the relative does not wish us to be consulted at all, the decision should depend more on long term overall benefit to the relative.

The Family can provide much valuable info to clinicians with careful questioning:

- History of developmental stages &
- History of changes in relative, triggers, what makes things worse, what calms

- Current symptoms & observable signs & frequency of signs, eg sleep, degree of self care.
 - This is particularly useful info when person presents temporarily as 'well' enough to not warrant admission
 - Degree of insight at least as far as expressed to family
 - History of previous treatment and its effects
 - current progress and responses to treatment, side effects
 - Some idea of medication compliance.
 - Noting early warning signs of relapse, self harm, substance use.
 - Noting any other needs the person may have, for recreation, social skills training, supported housing etc.
 - Current family circumstances/family dynamics
 - Family / supporter expectations from/about the service
 - Contribution to care plans
- (should get collateral information from person's peers, colleagues, friends)

Without breaking consumer Confidentiality

All this information can be provided by families without clinicians revealing confidential personal information about the consumer to the family where the consumer may not consent. We don't need to hear their particular bits and pieces which may be humiliating to the person. Sometimes we need gentle assistance in realising that too.

Sometimes families have a need to know

However, there are certain things that supporters should be made aware of in the consumer's safety and long term interest especially if unwell enough to need to live at parental home for support. In spite of the value of confidentiality, and consumer right for privacy, sometimes families have a need to know:

- what dangerous medication side effects look like and who to contact when they are noted. (chemist print-outs).
- How to respond more appropriately to manic, challenging, & withdrawing behaviours, or to delusional / paranoid material.
- Who to contact and at what stage when signs of relapse are observed.
- What are the signs of suicide and when and who to contact if noted.
- What to expect from the condition, some ideas on how long it could last in order to plan their family lives.
- What to do if the person stops taking their medication.

Families / supporters do not necessarily even need to know the diagnosis if the consumer is rational and does not want this conveyed. That's OK, if they contact ARAFMI, we can still give options on how to respond to the challenging behaviours and likely relapse signs.

Clinicians and Families

Clinicians should help families assist the recovery process. We are often the person's principal supports and as such sometimes have a need to know particular information in order to provide appropriate responses. Providing certain limited but appropriate information (perhaps with service provider documentation) about the relative may make recovery easier for consumer and family alike otherwise we may inadvertently get in the way by responding intuitively to challenges when counter-intuitive responses would be more therapeutic. We all want the consumer to get as better as possible in the shortest time possible.

Clinicians can help recovery more by:

- acknowledging the appropriateness and validity of ongoing anger & grief (extended and protracted in many situations), etc in the supporters. This may alleviate some caring burden & allow us to be more relaxed and therapeutic in our responses.
- Encouraging the family to set appropriate boundaries to their involvement, to prevent stifling the relative's initiative and opportunity.
- Encouraging us let our relative learn from their own mistakes & glory in their own successes

Family confidentiality

When families do contact a clinician then the same confidentiality should apply between family and clinician as between any doctor and patient. Several times lately we have heard how a responsible family member tells a clinician important information that needs to be heard by the clinician, who then has reported the source to the consumer. When clinicians don't keep confidentiality with supporters, existing tenuous family relationships are harmed further. When someone lacks enough insight, the person may not appreciate our informing actions as help seeking.

Concluding remarks

Much needed clinical information can and should be heard from family/supporters without personal information about the consumer being divulged to the family. This will lead to far improved clinical outcomes, in terms of diagnosis, treatment, healthy family functioning & planning further interventions.

I believe that rights and needs need to be balanced with each other and that there is little to be gained from holding one value, in this case, confidentiality, as an absolute value over and above all others at all times.

For free Government services:

Please phone the central office if seeking non-urgent help: ph 6233 6011

Urgent assistance: phone the Crisis Assessment Triage and Treatment Team (CATT)

Ph 6233 2388 or **1800 332 388** 9am til 10.30pm every day of the week.