{ *The Maine Connection –
an inclusive, volunteer,
consumer community* }

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The Maine Connection — an inclusive, volunteer, consumer community

It is often convenient to ignore the reality that communities exclude as well as include; religions, clubs, associations, unions, workplaces and political parties are broadly inclusive, provided that potential members share basic philosophical beliefs.

The **Maine Connection** is inclusive of people, ideas, therapies and beliefs. It will welcome any community member who is supportive of its aims and maintains that all people are best capable of mapping their own path to recovery and that the inevitable detours are sometimes helpful learning experiences. It seeks to support people in their recovery, in the ways that they choose. That foundational statement reflects our desire to be inclusive and defines our boundaries; we don't believe that '*one size fits all*,' or that '*recovery*' is an *event* rather calling it a process or a journey. While people with a '*program agenda*' are not excluded, we have found that they look elsewhere when they are met with members' preference to maintain the diversity of views the group has established.

We began to meet on a regular basis in May, 2004; by October 2007, we had fleshed out our core principles and aims; our core **principles** are brief and simple; each of us:

- has unique knowledge of our own lived experience;

- makes meaning of our own experience;

- is the expert in our own experience;

- is the expert on our own mental and emotional status;

- has expert knowledge of 'what works' for us;

- is the expert on establishing our own needs;

- is equally privileged in being heard.

Our **aims** reflect our philosophy and core principles:

- To develop and maintain an inclusive, supportive community of people who have experienced mental health problems, emotional distress or social isolation in the Mt Alexander Shire;

- To provide supportive advocacy for those who request it;

- To support people to achieve their personal goals in physical and mental health, in developing and maintaining financial independence and in participating fully in the local communities of their choice;

- To provide members with opportunities for paid work;

- To improve services for people in the Mt Alexander Shire;

- To improve public mental health services in the Loddon Southern Mallee Region and across Victoria;

- To provide an independent source of advice to community groups who wish to provide mutual support, advocacy and self-help to members of their own communities.

From the onset, we wanted to be *inclusive*; one of the main reasons members felt a need for the Maine Connection, was the difficulties experienced by some people in accessing services or being discharged from a service without consultation. People had sometimes been excluded from learning activities because they had the '*wrong*' diagnosis. The first real decision members took was that we would be inclusive - '*a support and advocacy group for people experiencing mental health problems, emotional issues or social isolation*'. If somebody wants to come, they are welcome. We have no criteria for attendance and we don't ask for diagnoses or referral forms. People are free to disclose as much, or as little, personal information as they choose. Different groups of people, diagnosed with a mental illness, will have different reasons for wanting to start their own community-based group. Perhaps the single essential reason is that a number of people express a need for it. If that need isn't obvious, then perhaps discussions around some of the points in this chapter will determine whether the need exists in your area.

In Mount Alexander Shire, based in the Central Victorian Regional City of Castlemaine, the need was first expressed as people wanting a space of their own, a place free of clinical and community workers, where discussions would not be censored, assessments not made, criteria of admission not even considered let alone enforced; welcoming of the community as, we believed the community ought be welcoming of us. This is one of the reasons why we think of ourselves as a *consumer community* rather than a consumer *group*. So, given that our motives and philosophies (whatever they might be), have led us to try to start up a *group*, where do we go from here?

Getting started

Establish that there is a *need* for a consumer-run, consumer-developed and consumer-controlled group. Some of the reasons given in this chapter might be useful starting points for a discussion.

Establish that there is a *commitment* by at least a couple of people who will turn up to meetings for 6 months, whether or not anybody else does.

Establish the *time and place* for the next meeting of the group, on a day suitable for most people, at a time that allows for school pickups and other essential activities.

Location

Maybe the most important question of all! Meetings ought to start immediately, otherwise you lose the momentum of the first flush of enthusiasm. Unless you've already got a venue, you might have to meet at someone's home. This is rarely a good option, but sometimes necessary. We did it for the first few weeks. The first meetings need to allow plenty of time for ideas about possible venues. Church halls, sports clubs, community halls, Community House, Shire facilities are some of the ideas we threw around. Ask people who have time to see what they can find out and bring to your next meeting; two of our members found a terrific hall, with kitchen facilities and secure space, owned by the Office of Housing and managed by the Shire. We've used this space ever since (rent-free, because we've always attracted some local residents as members). Our other space was *The Shed*, a disused commercial chook-shed, just out of town and owned by one member.

How often?

How often we want to meet depends on a lot of things: how often do people *want* to meet; how often will someone *commit* to attending? We decided on once a week, from 10.30 till 2.30, with options to scale up or down, depending on how we went. From August 2005 until March 2012, we met twice a week, which allowed some who couldn't make it on Tuesday to come on Friday afternoons (1-4). Since then, we have reverted to one day a week by consensus. This summer, for a change, at the suggestion of one of our newest members, we'll have a few evening meetings at the local BBQ area at the Castlemaine Botanical Gardens, also giving workers and students a chance to attend. If that works, it will probably become an annual fixture throughout the daylight-saving period.

Funding

Start thinking about finances; knowing that there will be a cuppa and biscuits encourages people to attend the group. Knowing there's a charge, however small, will keep some people away, some of the time - and often, they will be those who get the most out of the group. For donations, try the local Shire, service groups like Rotary and Apex, churches, mental health clinical service, your MHCSS (formerly PDRSS), your supermarket or from anywhere in the local community. Our MHCSS, St Luke's, gave us a 'seeding grant' of $500, which gave us a terrific start. Try to access 'undirected' funding, which can be used however members decide. We've used ours to provide morning/afternoon tea and a weekly meal for whoever turns up. We have been incredibly

fortunate that a local philanthropic group, the *Angel Fund*, provided us from the beginning, with finances to offer a free meal and morning and afternoon tea.

Grants

Your local Department of Health office provides a small Health Self-Help and Disability Self-Help Funding Program, for *'meeting costs'* each year which will provide for renting a space, utilities, paper (programs, newsletters etc.), archiving requirements (folders, filing etc.). We've applied for several grants, from a variety of sources; the YMCA offered an opportunity to pilot Mental Health Camps; they had grants provide 2 camps and we received a grant ourselves for a third one, through BankMecu with whom we have an account. The Shire offered funds to run a Pilates program for locals who could otherwise not afford them.

Records

Financial records are essential for group harmony and public 'accountability. Concerns about spending are easier to deal with if receipts for monies spent can be shown; a simple spreadsheet is all that's needed, plus a safe place for storing documentation.

Attendance records provide a useful 'history' of the group, also recording visitors; first names are sufficient. We don't keep personal files on anyone and believe this is critical, to ensure people feel free to express themselves, not being judged or assessed by others. They also provide data[52] which can be useful in applying for grants or other funding.

Membership

Be inclusive, which also means welcoming visitors. We've had consultations (more than 30, most of them 'paid' in some way), visits from members' case managers or key workers, as well as Council staff, who have given us opportunities to become involved in community activities. We also decided to charge no membership fee, so that nobody would be excluded because of poverty.

Relationships

Let the community know you exist; our first and now oldest relationship has been with *VMIAC*, Victoria's peak consumer body, who have been readily available for practical and moral support. *Our Consumer Place* was founded in 2007 and provides another valuable avenue of information, support and expertise. The *YMCA* supported us to have an annual group camp for three years and we've run 2 of our own since then, camps becoming a biennial event, the keenest camper among us collecting small amounts over 2 years, till we've all put in $250. That was enough to have camps, at Warrnambool and Picnic Point, in shared cabins, leaving enough to start the next camp fund. The local *Neighbourhood or Community House* may provide a temporary venue and activities as well as lots of practical, local advice. Community Mental Health and your local *MHCSS* (if you have them) can let people know when and where you meet. *Local Shire (or Council)* contacts are useful; a large amount of local knowledge is held by Council workers. The *Castlemaine Peace Choir* became a focal point for many members to engage with the wider community. It's a Neighbourhood House program, partnering with the Maine Connection, St Luke's and Windarring (a local disability service).

Decision Making

The disempowerment many consumers feel is part of what creates the need for this kind of group. Decisions don't have to be made till there is agreement; taking the time to get people on board - or to realise that they aren't on board - is essential. Things can always be revisited. Part of becoming re-empowered is learning to say *no*. In late-2004, some of us wanted to circulate a brochure advertising the Maine Connection in the community; several people objected and there was a clearly-stated fear that we might be '*taken over*' by outside people. The brochure was finally put out less than 12 months later, but everyone was happy with it by then, confident that the group was strong enough to survive.

Activities

These depend on decisions, the group makes, as well as opportunities that open up. *Drop-in*, now a dirty word for most support services, is an essential feature of many people coming to terms with what's happened and is happening to them. Unstructured social time is often an opportunity for people to gather their breath, reflect on their present and past circumstances and work out, in their own time, where, when and how they want to get on with the rest of their lives.

"...it's just a bunch of locals getting together to help each other out where we can."

Belonging to a community is one of the primary reasons people are a part of any group. Many consumers feel isolated from their original communities (family, church, clubs, workmates, friendship networks) because of the circumstances surrounding their illness and their own or others' stigma. Feeling 'at home'

in the group is often a first step to dipping a toe back into the wider community. Re-entry to the wider community is easier when you know people, who are already part of the community, through their own social networks. *Inclusiveness*, inviting people to visit the group, is often a way of breaking down the seeming *exclusiveness* of the wider community. Communities eat together; it's part of the building and maintaining of community. Our first donations were used to provide morning tea for those who came; we've always been able to offer all-comers a cuppa and a nibble. The thought of a cuppa can be the deciding factor in whether someone leaves home on a miserable day. A community meal, as often as the group can provide one, helps people bond. We've been very fortunate that our major benefactor, the Angel Fund, believe in the importance of communal eating even more strongly than we do!

Community is important to every one of us. Social research has shown that people who have strong and multiple community connections enjoy better health, are happier and live longer.

Mental health services often exclude people. Public mental health services are funded to provide a service to "*people diagnosed with a serious mental illness or disorder;*" they are also expected to discharge people when they need to accommodate new clients, or believe the clients no longer need the service. Unfortunately, decisions about who gets access to a service and who doesn't are ultimately made by the service, often with little or no consideration of the person's own view of their needs.

Relationships with friends and family can be lost along the journey through mental illness and living in poverty can mean that affordable chances to socialise are hard to find. People can lose the

confidence to socialise in the broader community, especially if they have felt the stigma of having a mental illness. Many consumers say that they would like, or need, to belong to a community of other consumers - people who won't judge or who can understand where a person's been and what they might have been through. This isn't unusual: women, lawyers, teachers, veterans, hearing-impaired people, fishermen, and so on ... all people enjoy the company of others who speak the same language, who we feel can understand us.

The Maine Connection is proud that we are a 'community' rather than a 'service'; we've formed strong views about social inclusion, which seems to have two related but different aspects; the first aspect is about human rights as described in the Victorian Charter of Human Rights - including access to housing, employment opportunities, equality before the law, freedom of expression etc. The second characteristic is about the needs most of us have, as social beings, to enjoy the company of others. We support human rights through advocacy, education and being eager participants in research projects, by a variety of organisations, including the Department of Health. We provide our needs, as social beings, through our own consumer community itself as well as by inviting community members to join us and by being open to opportunities such as table tennis, choirs and camping programs that come up from time to time.

Why do mental health services actively work to break down or discourage consumer communities? Although most services have a goal of social inclusion, as a strong policy statement, they design their programs around getting people involved in the broader community rather than supporting a community of consumers. It is not the only community to which members belong, but it is a strong place where people can feel

included and safe, get their bearings and make decisions about where they want to go.

Clinical and Psychiatric Support Services, while often necessary, exercise a large degree of control over us, through their ability to subject us to involuntary treatment and to deny us treatment or support. Because the Maine Connection is socially inclusive, our community is stronger; we have developed close friendships with each other, which carry over into time spent together outside the gatherings of the group. In the time we've been together, groups of members have become part of the local table tennis competition, gone camping regularly, been foundation members of the Castlemaine Peace Choir, become involved in buying and selling at local garage sales and organised, or helped, at the three Mental Health Week Concerts we've put on with the help and support of local musicians and our local MHCSS.

Being inclusive has considerably expanded people's opportunities to re-engage with the broader community and the consumer community we've established has helped people develop the confidence and self-esteem that are critical to successful community engagement.

How does the Maine Connection work?

We currently meet on Tuesdays from 10:30 till 2:30, at a community hall in Castlemaine. There is no charge or membership fee; tea and coffee are provided and we have a light lunch, nothing very fancy. Maybe once a month we have an '*agenda*' – consumers from another town visiting, a consultation with a government or academic department, workers from the Shire or a health service, a birthday or Christmas/New Year party. For most of the time, it's just the people who turn up on the day and we talk about our lives, our

circumstances, our hobbies, TV, movies, sport and current events. If anything interesting in mental health has happened, it will usually get a run; if someone's struggling we'll talk about that – if they want. Mental health probably gets less attention than physical health does, which is unsurprising as we all know they're inseparable, even if that seems to escape psychiatry.

Consumers know it is essential to talk about their experiences of illness, trauma, treatment and side-effects, as one way of learning to deal with their circumstances. Some topics, like self-harm or suicide, need to be treated sensitively, but making certain topics taboo, as some mental health services do, doesn't help people address their feelings and fears. It is difficult to quantify the importance of the ability to talk freely, to imagine and suggest, to explain and explore without fear of being judged.

When we started, we probably wouldn't have said that education was one of the reasons we wanted to start the group, but we like the fact that we've learned a lot from each other along the way. All education, happening within a group like ours, is fundamentally different from that provided by a clinical or NGO support service. First, it often '*happens*' rather than being provided. Most education for consumers by consumers concerns basic questions, like what is mental illness, what is mental health and what might recovery, for me, look like. Another major topic concerns the '*side-effects*' of treatment. These discussions take the form of enquiry rather than instruction, as members seek to clarify their own perceptions, of their experience, in the light of others' experiences and beliefs. As members of the wider Australian community, members share many of the wider community's beliefs, fears and prejudices. Our own fears of and prejudices against mental illness are challenged by the

discussions that take place and sometimes reveal to us our own stigma which works against our 'recovery' - whatever those terms might mean to each of us.

There is also another side to education within consumer groups. Knowing how the mental health system works is important knowledge and plenty of formal information about it comes from official documents. For consumers, however, the system rarely seems to work the way the official version claims; members and visitors telling their stories helps people fill the gaps between rhetoric and lived reality. Most of all, we've shared ideas, knowledge and skills; everybody has skills and we found that, through the group, we have used and developed our existing skills and learned new ones from each other. Support provided among consumers (peer support) is totally different from that coming from any other place; giving support to others also greatly benefits how we feel about ourselves.

A code of ethics - do we need one and what might it look like?

A code of ethics, for consumers, would list those behaviours that would be seen as appropriate for consumers, who choose, in solidarity with other consumers, to join together with a common purpose. A *Code of Conduct* often arises out of a stated or unstated code of ethical behaviour and is used by a range of organisations and groups. The simplest code of ethics is the Golden Rule: "**Do unto others as you would have them do unto you.**"

When the subject of a Code of Conduct was brought up, at an early meeting of the Maine Connection, the strong response was that it was unnecessary: "*We're all adults, we know how to behave.*" While we haven't found a need, since then, to develop a Code of Conduct or Ethics, discussions about ethics are inevitable when talking about involuntary hospitalisation, treatments (including ECT) and medications. The following general points about what a Code of Ethics, for consumers, might need to address have all been made at various times in the group:

Confidentiality - *what's said in the group stays in the group; open discussion requires trust in each other. If people can't be assured of confidentiality, then what they speculate about or reveal about their past or their ambitions will be less useful to themselves and to the group.*

Respect - *for yourself and for all others; many consumers have experienced profound disrespect from service providers, family and friends. It's crucial that we respect each other. Our self-respect also often suffers following a diagnosis and it is important that each of us actively supports self-respect as well as acting respectfully to others.*

Tolerance - "***Think for yourselves and let others enjoy the privilege to do so too***." *People's experiences and beliefs result in a wide variety of views about all sorts of issues and events. Lively disagreement doesn't have to end in anger. It has a few times and we've offered people a lift home, if that's required, but they have to sort it out themselves - and generally, they have.*

Finding common ground - *It is important to keep in mind that, as consumers, we have much more in common than we have differences. We need to be united to achieve our shared goals and points of difference between us shouldn't get in the way of that.*

Honesty - *Hidden agendas can be very disruptive to any group; be 'upfront' about what you think, what you are hoping to achieve by a certain course of action, what you want from the group.*

Public responsibility - *Maintaining a respectable public image is important to the success of any consumer group, particularly if members want to have an influence on mental health policy and service delivery. Alcohol and illegal drug abuse will alienate many in the community and many potential members will stay away if the group has a reputation of condoning these.*

Peer support - *Simple. We support each other.*

Empathy - *All members have experienced distress of various kinds. Being able to relate other people's difficulties to periods in your own life is a powerful tool, in developing respect and tolerance within the group.*

Reported benefits of an inclusive, volunteer, community consumer group

Why do we believe that a community is the fastest and most effective way of finding ourselves again - not who we were, but who we have become? Active members of the Maine Connection were asked what they found useful about attending the group:

Knowing Yourself - *Getting diagnosed with a mental illness changes your life. A self-run support group provides a regular opportunity to think and talk about how you've changed and how your world has changed. Other people's stories and reflections help you understand your own place in the world.*

Knowledge of Mental Illness, Mental Health & Recovery - *Mental illness, mental health and recovery are all very loosely defined and there is plenty of argument about the definitions used. There are no physical tests to determine mental illness or mental health and recovery means different things to each of us. Informal discussion groups help people understand and define their own levels of distress and well-being and enable them to make decisions about their own recovery journey.*

Knowledge of the system - Improving mental health services - *Discussions about our own circumstances and those of others, plus stories of our experiences with the mental health system, invariably raise ideas about ways in which the system could be improved. They also help people form ideas about ways of minimising their own risk of relapse into un-wellness. The availability of advocacy as well as information speeds this process up.*

Normalising your condition - *Stigma and its more punishing offspring prejudice and discrimination stem from fear and mistrust of difference; increasingly it is clear that mental illness is more the rule than the exception in society and that it is the **extent of distress, experienced** by people, rather than the existence of **symptoms** which determines whether or not an individual receives a diagnosis. Freely discussing symptoms, medications, side-effects and the experience of mental illness can work wonders in removing that sense of difference.*

Regaining control of our lives - *One of the most distressing effects of a diagnosis of mental illness is loss of trust in ourselves; in many cases, other people lose trust in us too and, as a result, we may lose some control over our lives. Clinical and non-clinical services add to this sense of*

not being in control by the use of involuntary treatment and requiring people to follow their programs to receive a service.

Building self-confidence and esteem - *Self-confidence and self-esteem are based on our perceptions of ourselves. If we have lost those, through the diagnosis of mental illness and all its consequences, we need to develop new ways of 'seeing' ourselves and of understanding who we have become.*

Developing a community - *Communities take time to develop; despite members' insistence on inclusiveness, it took more than 12 months before we were confident enough, that new members wouldn't 'take us over,' that we could print and distribute flyers advertising our existence and welcome new people. Much of that time was spent in refining our ideas about what's been written above and determining what we wanted the Maine Connection to be.*

Rebuilding social networks - *Consumer communities may often be necessary as part of re-establishing yourself in the world, but it is rarely enough. Many of us have developed a belief that the wider community has rejected us and until our social networks branch out into that wider society, we can't realise our potential. For many, stepping outside the consumer community is best done with friends. We found that bringing the community into the Maine Connection whenever we can has worked for us.*

Creating a safe place for ourselves - *Creating a feeling of safety for people is essential; sharing food initiates contact and is familiar and welcoming. Confidentiality ("What's said in the group stays in the group") is essential for people to feel safe. A friendly environment, casual and informal talk, including everyone in conversation, tolerating different points of view, respectful behaviour by and to everyone, are simple but effective ingredients in developing a feeling of safety.*

Exercising your sense of humour - *Laughter is therapeutic and consumer support groups ought, above all, to be fun.*

Endnotes

52. Eg. more than 300 people have attended at least one meeting of the group, 93 having been potential or actual members, 99 paid workers, 65 family/friends, 63 visiting consumers and 7 volunteer alternative health practitioners.