



The News Magazine of the Center for Family and Consumer Advocacy and Support

Center News • 2nd Quarter 2010

In This Issue...

Mental Illness and Suicide: A Family Guide to Facing and Reducing the Risk.....	1
WPA Project on Partnerships....	3
“Breaking the Silence” in Gozo..	4
‘Get Well Soon’ cards for people with mental ill health.....	10
Miscellany	10
Unravelling the Mysteries of Anti-Stigma Strategies.....	11
Après le décès d’un voyageur ...	15
News from the Groups	18

Mental Illness and Suicide: A Family Guide to Facing and Reducing the Risk

A new publication from the WFMH Center for Family and Consumer Advocacy and Support

WFMH has just completed its guidebook ***Mental Illness and Suicide: A Family Guide to Facing and Reducing the Risk*** copies of which will soon be available on CD. The rationale for the guide described in the introduction, is introduced with a quote from Dr. Benedetto Saraceno, Director of the Department of Mental Health, World Health Organization and is as follows:

More than 90% of all cases of suicide are associated with mental disorders such as depression, schizophrenia and alcoholism. Therefore, reducing the global suicide rate means effectively addressing the serious and growing burden of mental illness around the world.

It has become alarmingly clear that serious mental illness (SMI) plays a substantial part in suicide. The UK Department of health advises that “approximately 25% of all people who die by suicide have been in contact with mental health services in the year before death”.

It is for this reason that the World Fellowship for Schizophrenia and Allied Disorders (WFSAD) began researching the consumer, family and medical literature in order to put together a guide that would make people aware of the risks for suicide that are faced by families and people with SMI. As WFSAD was amalgamating with WFMH, the Center for Family and Consumer Advocacy and Support was established by WFMH and became responsible for the guide that has emerged from this work.

The overarching goals for the guide are:

- To help reduce the risk of suicide among people living with serious mental illnesses through focusing on informing families/ caregivers
- To build awareness and skills among family caregivers of people living with serious mental illness
- To introduce preventative support systems to families in all parts of the world (serving families and caregivers in both developed and developing countries)
- To recognize the emotional distress and trauma from suicide and suicide attempts that is common to all families no matter where they live



Guide (Eng.) 55 pages;

*Facilitator's Handbook
(Eng.) 22 pages.*

Report by D. Froggatt

We consulted with family and consumer organizations and searched the internet for materials relevant to families and consumers. We interviewed families that had lost someone to suicide and those who had lived through an attempt. We also consulted with those who had lived through an attempt themselves.

We were glad to have the help of the Uganda Schizophrenia Fellowship and the UK charity Basic Needs in testing a questionnaire “live” at meetings of their members in Kenya and Uganda, to find out about attitudes and beliefs in the developing world. The results gained from this questionnaire played a significant part, not only in the development of an online survey sent to our members, but in the development of the project.

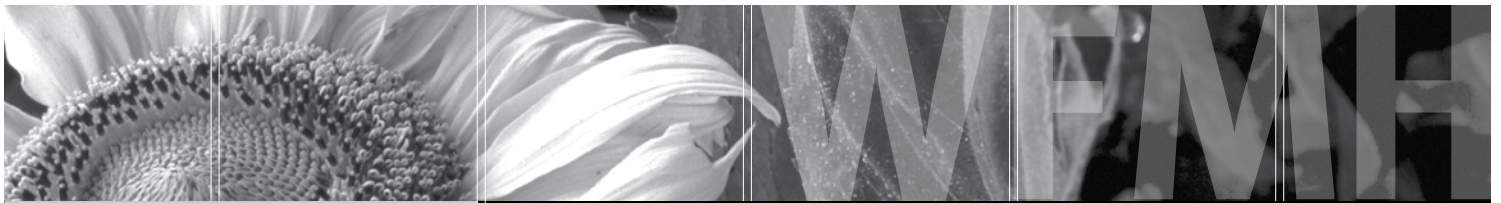
We did not want the guide to have the feel of a text book. Our aim was to appear to talk comfortably with anyone for whom the title held interest. The guide begins with “talking about suicide” and puts forward the questionnaire that we had previously tested. From there the guide goes on to trying to understand why people take their lives and to seek to know what is going on in their minds.

Practically everyone who has learned anything at all about suicide knows the words “risk factors” and “triggers” are significant. The guide divides these into internal (emotions and feelings) and external (events and influences) and discusses ways to divert or overcome these. Proactive ways of helping to avoid suicide are discussed, as well as what happens after a suicide attempt and bereavement after a suicide. There are appendices listing books, articles and websites relevant to the subject and a list of programs around the globe that can help people in distress.

There is also a **Facilitator's Handbook** for those wanting to deliver this material as a workshop, perhaps in the atmosphere of a family agency or support group. The Kubly Family Foundation based in Milwaukee, Wisconsin, U.S. is to sponsor a workshop in March of 2011.

A limited number of hard copy guides will be available, but since it is hoped to disseminate this material far and wide it will be most readily available on a CD from the WFMH Center for Family and Consumer Advocacy and Support. Those requesting the CD will be able to print it out as a book if required. The CD will contain both the guide and the Facilitator's Handbook in both English and Spanish.

The project was put together by Diane Froggatt, former executive director of the World Fellowship for Schizophrenia and Allied Disorders (WFSAD), as part of a WFSAD project that was originally partially funded by H. Lundbeck A/S. The Spanish translation is by Gail Grossman, M.D.



World Psychiatric Association Project on Partnerships for Best Practices in Working with Service Users and Carers

Information on the above project has recently been published in the journal *World Psychiatry* and is also available on the World Psychiatric Association (WPA) website www.wpanet.org.

The article, by Professor Helen Herrman, reports that the WPA invited service users and family carers to join in its work as members of a Task Force on Best Practices in Working with Service Users and Carers. The task force is preparing recommendations for the international mental health community on this subject. Below is an extract from this article:

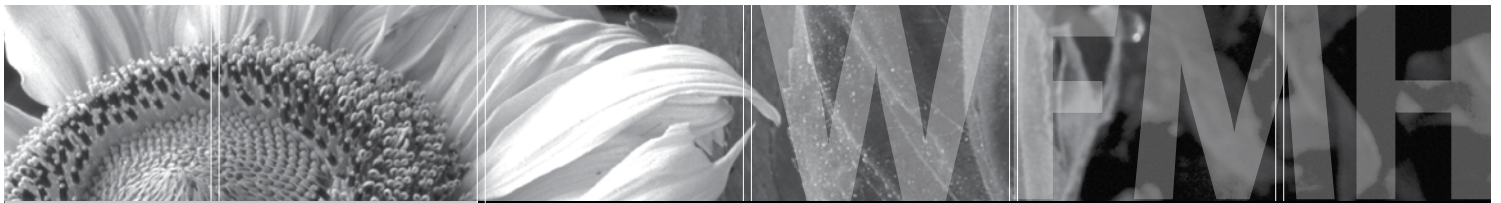
Service users and carers up to the present day have the regular experience of stigma and discrimination in the community, poor access to care for mental and physical health problems, and treatment under conditions that rob them of respect and dignity. Psychiatrists join in calling for their inclusion in decisions related to treatment and rehabilitation, the development and management of services, the building of a research knowledge base, the development of policy, and the resolution of problems at any level, especially social exclusion. . . .

The taskforce has defined the primary need to develop a unified approach to advocacy for mental health and human rights at country and international levels. Adequate support for mental health services and improvement of mental health in any population require a united voice. Achieving this will need support for the capacity of each group to work effectively in partnership. As service users and family carers typically lack the power to interact equally with professionals and government decision makers, assistance in developing this power is mutually important for them and for the WPA and the wider international mental health community. . .

A draft series of ten recommendations about the changes required begins with the declaration that respecting human rights is the basis of successful partnerships for mental health. The second recommendation is that legislation, policy and clinical practice relevant to the lives and care of people with mental disorders need to be developed in collaboration with users and carers. The series continues with a recommendation that the best clinical care of any person in acute or rehabilitation situations is done in collaboration between the user, the carers and the clinicians. Education, research and quality improvement in mental health care also require this collaboration. Other recommendations include enhancing user and carer empowerment through the development of self-help groups; participation in service planning and management boards and the activities of professional societies; employment of people with mental health disabilities in mental health service provision, user-run community centres and psychosocial clubhouses; and the creation of inclusive local anti-stigma programs. Each country will need specific guidelines to apply these recommendations.

The next step is a wide consultation and developing an advisory network to include people and organisations with needed expertise. . .

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Center News • 2nd Quarter 2010

Membership of the taskforce is made up of the following people: three members with a background as service user (Bhargavi Davar, India; Sylvester Katontoka, Zambia; and Jan Wallcraft, UK), three with a background as family carer (Diane Froggatt, Canada; Hussain Jafri, Pakistan; and Sigrid Steffen, Austria) and six psychiatrists associated with the WPA (Michaela Amering, Austria; Julian Freidin, Australia; Helen Herrman, Australia - Chair; Solomon Rataemane, South Africa; Henrik Wahlberg, Sweden; and Richard Warner, USA). The members were appointed as individuals, although several also hold leadership positions in relevant organizations. Chris Underhill, founder and director of Basic Needs, is special adviser, as are two members of the WPA Committee on Ethics, its Chair Sam Tyano and Afzal Javed. The World Health Organization Department of Mental Health and Substance Abuse is helping by offering its experience and advice.



A personal story given at the seminar “Breaking the Silence” in Gozo, Malta recently

By Eleanor Murphy

My sister Shirley was born in 1952 in Bristol, England. She was an energetic child and enjoyed climbing trees, looking after animals and swimming competitively for her school. Shirley had a happy childhood with a sister five and half years older, and a brother seven years younger.

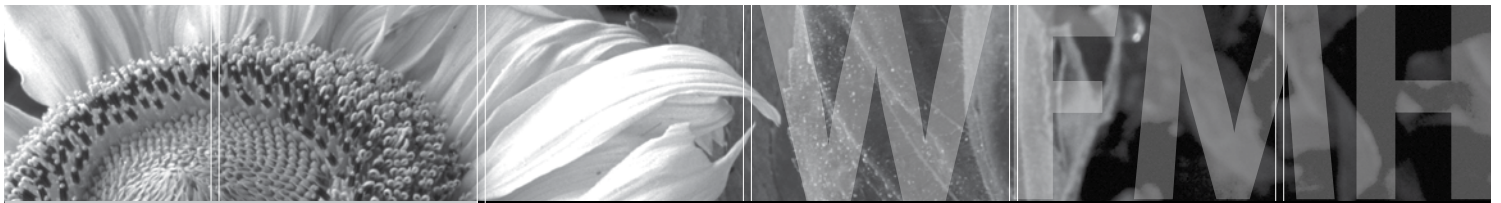
Shirley became mentally unwell when she was 16. She was at school when her behaviour became erratic and she had great difficulty concentrating. Her thoughts were very muddled and her speech disjointed. At the time our family doctor put her erratic behaviour down to being a ‘troublesome’ teenager. Unfortunately, her symptoms were much more serious than that.

I was 22 when she became ill. It was a very complex and confusing time in the life of our family. We felt overtaken by an emotional tsunami. Add that to an emotional freight train and it goes some way to explain what threatened to engulf us. **Nothing** could have prepared us for her illness.

Shirley’s head teacher had recognised from her own experience that Shirley was developing schizophrenia. This didn’t mean much to us at the time. Now we know that schizophrenia is a brain disorder that affects the way a person thinks and sees the world. It can be severe and disabling and it has affected people throughout history. For the next 2 years, my family saw a psychiatrist or psychologist on a regular basis. They were helping us to understand Shirley’s illness and how best to respond to very new and challenging behaviour.

Shirley’s head teacher had recognised from her own experience that Shirley was developing schizophrenia.

continued...



Shirley experienced psychotic episodes - being out of touch with reality. Psychosis is a symptom of schizophrenia. It is frightening for the person, for family; for friends and for people in the community.

Shirley had to leave school; there were no opportunities for her to say goodbye as she was too confused. She did however, have some awareness and it was enough that she was devastated to have to leave before it was her time to do so.

It is common for people with schizophrenia to have little or no insight into their illness. This is very difficult for friends and family members. They realise that professional help is needed but their loved one is not able to recognise this.

For a short time Shirley was admitted to a psychiatric ward in our local general hospital in Bristol. The idea at that time was that with the help of psychiatric medication she would improve and possibly make a full recovery. A quarter of people with schizophrenia diagnosed early in their disease go on to recover.

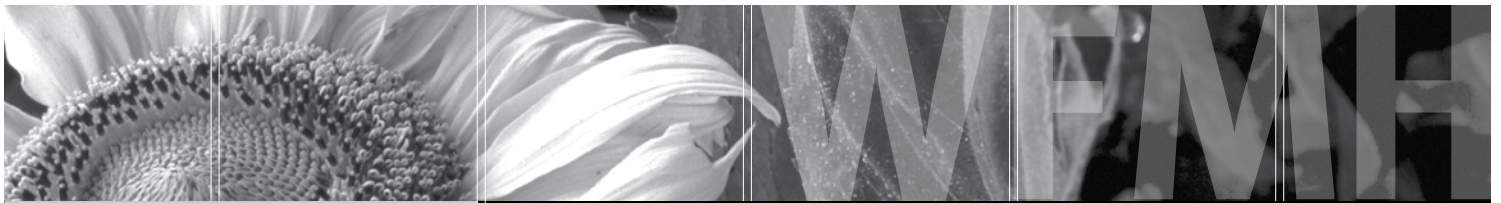
As a family with professional support we encouraged Shirley to share a flat with myself and a nursing friend in Bath, a beautiful Georgian city near Bristol. This would be part of her recovery process. The arrangement lasted three months.

Shirley had to return to Bristol to an acute psychiatric unit where she remained for some time. The medical staff there tried to balance her medication, which was the drug chlorpromazine (Largactil). (This drug was used widely in the 1950's.)

Shirley experienced psychotic episodes - being out of touch with reality. Psychosis is a symptom of schizophrenia. It is frightening for the person, for family; for friends and for people in the community.

We experienced many years of Shirley running around Britain, walking out of hospital, getting on trains with no ticket, arriving at destinations where station staff were confused and with little knowledge of how to cope. The only plus was that Shirley was always seen as an innocent and not wanting to deceive people. Her lovely basic personality shone through the muddle of her mind.

When I was working in Edinburgh in the early 1970's Shirley appeared unannounced with no money and no plans. This was difficult at the time as I lived in a nurses' home and was not able to put up a mentally ill sister. A very good friend and colleague helped us out for a few days. Then Shirley disappeared. Later when I worked in London she appeared at the hospital Emergency Department around midnight and announced that she needed to see me and stay overnight.



Center News • 2nd Quarter 2010

Shirley was physically very able and a keen walker and would be up and out before other residents were out of bed. Despite her physical strength and determination to get on with her life she was stuck at every turn.

I learnt very early on in my sister's illness that I had to know how to look after myself, for if I was to be a long term carer I had to be fit and able. I also realised that I needed good friends and colleagues around me. With these I was more prepared for my sister's unplanned visits.

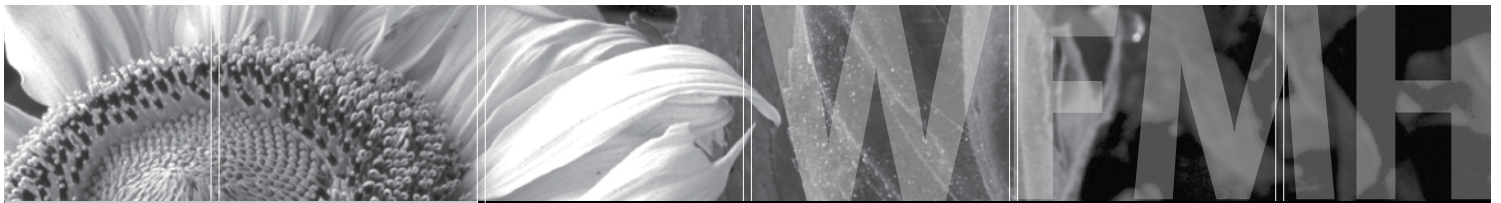
In Britain in the 1980's it was decided that most people with a severe mental illness would benefit from 'living in the community'. It was thought that patients became institutionalised - too dependent on being 'cared for'. So, in 1986 people with a severe and chronic mental illness were gradually 'moved into the community.'

For our family this meant that Shirley was moved from a long-term psychiatric institution where she had lived for about 15 years and shared a bedroom with 12 other patients, to the first Community Home of its kind in north Bristol. At this Home she would have her own room and all the care would be client centred. The idea was that the residents would stay for about two years and then they would be rehabilitated enough to move on to a house or flat where they would require less support but still have some supervision.

For a very short time it was thought by the professionals that Shirley was ready to go to a smaller unit where she would have support during the day if she needed it. At night there would be a carer in the house but she would be doing what they call 'sleeping nights'. The carer had her night room under Shirley's bedroom. Shirley was very unhappy in the house and she expressed this by moving her bedroom furniture around the room at night which prevented the night carer from sleeping.

Shirley was physically very able and a keen walker and would be up and out before other residents were out of bed. Despite her physical strength and determination to get on with her life she was stuck at every turn. Her mental level of functioning was diminished. If she had not been living in a mental health nursing home she would not have taken her medication, fed herself or managed to work in any capacity.

In the early years of this new arrangement I put in an enormous amount of time at her house as there were only two members of staff on any shift. I attempted to keep Shirley up to date with her physical health checks. It was gradually being realised by the government and health professionals that people with a mental illness were not receiving the same physical care as other members of the adult population and that this was to their detriment. Fortunately, now the physical health care of people with a severe mental illness is gaining recognition.



It is now a statutory requirement in the UK that all people with a severe mental illness have a twice yearly review entitled a Care Plan Approach.

While most people with physical and mental health problems live in the community, it is important not to ignore the needs of those who may be in hospitals and other long term facilities, including rehabilitation centres, long stay psychiatric wards and nursing homes. Research has shown that mentally ill people tend to die 10 – 30 years earlier than their mentally well counterparts.

At the time, non mental health professionals did not make allowances for the erratic behaviour of mental health patients and it could be extremely demanding on a carer to try and keep their sick loved one at the required place at the required time.

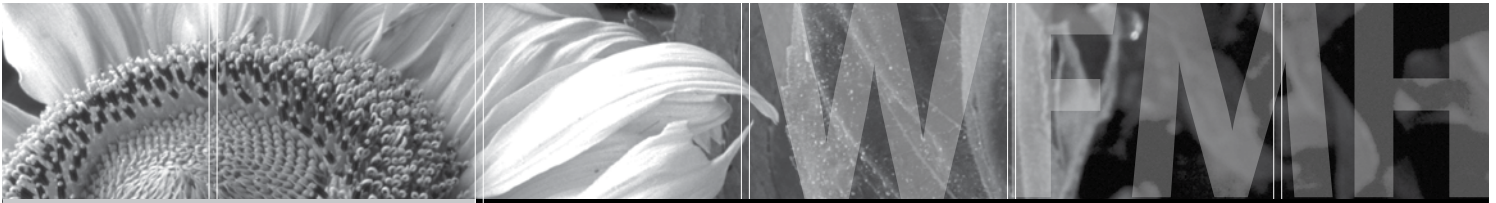
In recent years our government has legislated that allowances must be made. It is called 'making an appropriate adjustment'. Primary Care Trusts and other health disciplines have to incorporate this into their day-to-day practice.

When Shirley's home opened, the idea was that every resident would be able to keep his/her room clean and tidy. This plan may have worked for some residents but not for all and certainly not for my sister! It meant I became involved in keeping Shirley's room clean as her habits were not hygienic.

For many years Shirley's home was run by our National Health Service but in 1988 it was taken over by a private mental health care trust. Since then the standard of care has risen from good to excellent. All the staff involved in the care of the residents deserve their 3-star status. Staff turnover in the house is low and I believe this is due to good management. The staff are respected for the very difficult job that they do very well and *their own needs* are respected in the same way that they respect the individual needs of their residents.

Now that the central illness can mainly be treated with medication it enables the person to be cared for in a more holistic way. It is possible to consider their interests and desires, occupation and life style and helps facilitate a way of life that is right for them. For instance last year there was an opportunity to take part in an art exhibition with members from other mental health nursing homes. This gave those who participated the opportunity to define themselves in new way.

It is now a statutory requirement in the UK that all people with a severe mental illness have a twice yearly review entitled a Care Plan Approach. Carers are also given the opportunity to have their own needs re-assessed. In Shirley's case she has always expected me to attend her meetings while not attending herself, although she would be made welcome if she wished to come. In reality, the group meeting is more than she could tolerate.



Caring for the carers must be considered. Caring for anyone with a physical or mental health problem can be very onerous and create significant constraints which may be personal, social or financial as carers may have to give up work or reduce time spent at work.

It is a desire of the international mental health community that families work in partnership with mental health professionals. During the last 40 years it has most certainly been a two way process between Shirley's professional carers and our family. Everyone's input is important and no one person is more important than anyone else. I am able to be an advocate for my sister as we have always had a good relationship. She has seen my input into her care as vital to her situation and no-one in the mental health field has ever disputed it. Before a meeting I always ask her if there is anything she would especially like me to mention. The meeting is usually attended by her consultant, or his representative, the head of the home or her deputy. Her 2 key workers are likely to attend, one a trained RMN and the other an experienced care worker. Another member of the team meeting is Shirley's social worker who attends to make sure that Shirley's placement at the home is still suitable.

Mental health charities in the UK and Europe realise the importance of the carers' roles. Throughout the EU, there are more than 100 million family members providing care and support to a loved one with a physical or mental health problem. Not only must the reliance on these carers be **acknowledged** and **the impacts** recognised, but the role of carers may be pivotal in helping to promote positive health for people with physical problems and mental health issues.

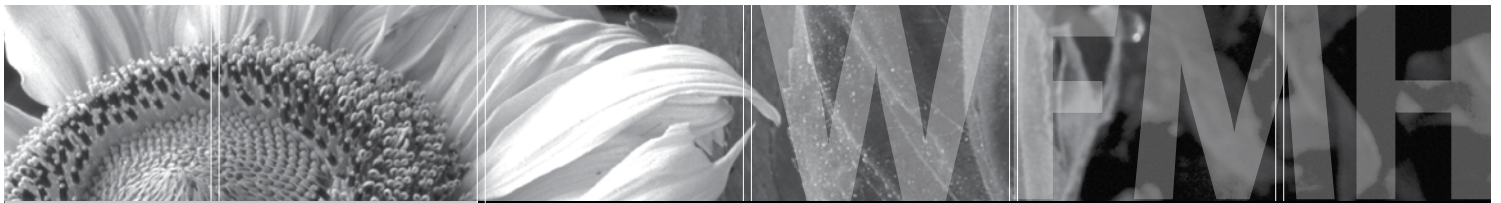
Caring for the carers *must* be considered. Caring for anyone with a physical or mental health problem can be very onerous and create significant constraints which may be personal, social or financial as carers may have to give up work or reduce time spent at work. I worked part time for many years to support Shirley and my parents, and also, to support my own recovery.

In December 2004 Shirley was diagnosed with breast cancer. It came to our attention when she was invited for a routine mammogram when she reached the age of 50. A year of treatment followed – Shirley would never have undertaken a routine breast check herself.

I should mention that both my parents were actively involved in the care of my sister; my dad died after Shirley had been ill for 13 years and my mother supported her for 24 years.

My younger brother is was only 9 when Shirley became ill and cannot remember a time when she was well. Therefore, he cannot understand the overwhelming sense of loss and trauma her illness caused.

I cannot understate the sense of bereavement I experienced when Shirley became ill. It was a long and complicated bereavement as she was alive and in need of enormous amounts of love and support. All these family



'Breaking the Silence' sponsored by the Malta Ministry for Gozo was held in April 2010. The seminar came about as a result of the desire of mental health professionals and families to raise awareness of mental illness and to assist relatives looking after those with mental health problems. During this seminar a branch of the Malta Mental Health Association was re-established in Gozo after an absence of two years. The new support group will provide assistance to persons with mental health and their families.

Eleanor Murphy is a nurse and family carer living in Bristol, England.

reactions are now well understood by mental health charities as families have put forward their experiences.

At the time none of my contemporaries had experienced life changing events and I found it hard to find a person with whom I could freely process my thoughts and feelings. My mother used me as her sounding board but I needed my own person with whom I could do the same. For this reason there are now sibling support groups across the UK.

RETHNK Mental Illness is the largest mental health charity in the UK. It has grown from humble beginnings in the 1970's. It is now a large organisation which covers all aspects of severe mental illness and looks to provide support and training for sufferers and their families. Support and training helps to empower families.

It is important for new families experiencing life with a sick family member to know that the more they can learn about the illness the more they will be prepared to deal with the challenges. There are now many organisations worldwide supporting families with a mentally ill member. There are also training programmes to enable families to learn the skills required to support their sick loved one. Meetings help families to learn more about both the condition and how to advocate for their loved one.

The incidence of schizophrenia is 1-100 worldwide. Not all people will present as my sister did all those years ago. Some will make a full recovery. There is a wide range of ability and disability under the umbrella term schizophrenia. Unfortunately, I believe that Shirley is one of the 10 per cent of sufferers who do not recover enough to be able to live a more independent life.

It so happens that in my working life I was a nurse. Many people have the capacity to care and you do not have to be a professional to do so. My husband has been a fantastic support during the years that we have been together and he really understands Shirley as a person as well as understanding how schizophrenia affects her. He is a good listener and he doesn't make judgements.

Thank you for inviting me to share my experiences with you.



'Get well soon' cards for people with mental ill health

The UK Royal College of Psychiatrists is selling a brand new range of 'Get well soon' cards designed specifically for people who are unwell with mental ill health. These cards have been designed in collaboration with service users, carers, psychiatrists and other mental health professionals.

The cards come in two striking and colourful designs. Inside the greeting reads:

"Thinking of you at this time. Hope things improve soon."

Research shows that people who are unwell with mental problems receive far fewer cards or messages of support than people with physical health problems, but a College survey shows that 8 out of 10 service users say that receiving a 'Get well' card would improve their recovery.

You may buy these on the RCP website at:

<http://www.rcpsych.ac.uk/mentalhealthinfo/getwellsooncards.aspx>

Or why not design your own!

*The cards come in two striking
and colourful designs.*



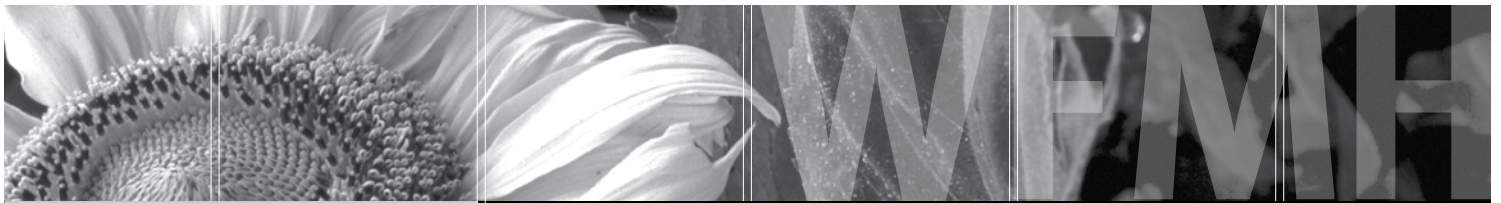
Miscellany

An Idea that creates optimism

The Black Dog Institute and Nikon Australia recently held a digital photographic competition with the theme Snapping the Black Dog: A photographic competition about hope and resilience in the fight against depression. The purpose of the competition was to capture the essence of depression through the eye of the lens. Each entry had to capture one of the following key messages:

- Hope and resilience
- Everyone deserves peace of mind
- Understanding depression and resilience
- Exercise for mood benefits
- Destigmatise and inspire
- Light at the end of the tunnel.

The competition closed on June 18. We hope the results will be posted online.



Miscellany

European Patients' Forum

This interesting site is for all patients not just those with SMI (serious mental illness). Nevertheless, its manifesto reflects the desires of those with SMI. This extract is taken from their website: www.eupatient.eu

Patients' Manifesto

The European Patients' Forum through its membership represents over 150 million patients – citizens and voters across the EU.

The Patients' Manifesto that we have developed with our members calls for vital new measures in three fundamental areas to improve the quality of health care delivered across the EU*:

- Equal and timely access to safe, effective diagnosis, treatments and support
- Better information and resources for patients to be partners in determining their care
- A patients' voice to be heard in Brussels and throughout the European Union.

Our current health systems can be unfair, divisive and fail to put the patients' perspective first. We believe all patients within the EU have a basic right to equal access to quality medical treatment, regardless of where they live, their status or their income.

** In our Patients' Manifesto we call upon the political groups within the European Parliament, MEPs, prospective MEPs, national representatives in EU Member States, and the new Commission, to commit to the legitimate rights and needs of patients and to make our proposals their priority.*

Our current health systems can be unfair, divisive and fail to put the patients' perspective first.

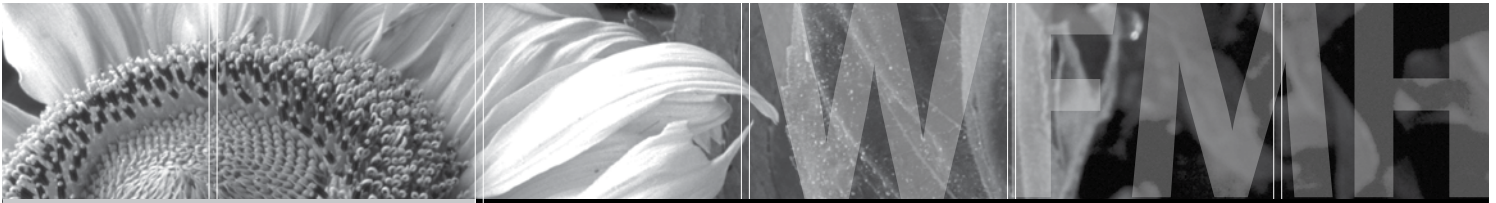


Unravelling the Mysteries of Anti-Stigma Strategies

By Marvin Ross

Most of us cringe every time we watch a TV show and see another episode about a serial killer or a murderer and learn that he or she has schizophrenia. When we hear of a particularly violent murder in the news, we tense up like an abused child or wife waiting for the next blow, fearful we will hear the S-word.

Schizophrenia does make good thrillers by lazy, unimaginative writers. Violence committed by mostly untreated people with serious mental illnesses does happen and each time it happens, it nullifies our anti-stigma efforts.



What then are the best anti-stigma strategies? From my readings, there is intense debate about what these campaigns should focus on. The two main concepts simplified are – ‘tell it like it is’ versus ‘let’s ignore the illness and just get to know the ill as people’.

Tell it like it is

Dr. Heather Stuart, a stigma specialist at Queen’s University in Kingston, Ontario, Canada, wrote that few antistigma initiatives have ever been empirically evaluated and their impact on the quality of life of people with mental disorders is unknown. She could only find six controlled studies on the efficacy of strategies that were evidence based – 3 from the US, 1 from Germany and 2 from Australia.¹

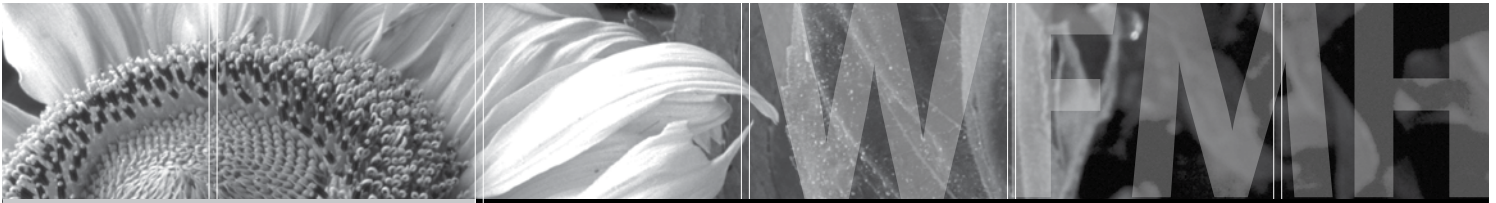
The most extensive of those studies and the one with the most relevance for this article is *Three strategies for changing attributions about severe mental illness* by Patrick W Corrigan, et al from *Schizophrenia Bulletin* (27)2. This study compared the strategies of Education, Contact and Protest. Educational programs replace myths about mental illness with facts. Protest programs present a morally untenable position about a group, followed by a rebuke. Contact, in this study, involved having one or two people present a 10 minute description of their severe mental illness.

Both education and contact led to attitude change while protest did not. “Contact seemed to improve public perceptions and recollections” while education “seemed to produce relatively broad effects.” Those who had education “seemed more willing to agree that persons with mental-behavioral disabilities benefit from medical and psychotherapeutic treatments and, therefore, have the potential to recover”.

A paper by Dr. Heather Stuart: *Mental Health Reform for the 21st Century*, is based on the results of anti-stigma campaigns conducted in Canada including the WPA *Open the Doors* campaign as well as evidence from a Canadian Senate committee report. In the section *Lessons Learned in Stigma Reduction* <http://economics.ca/cgi/jab?journal=cpp&view=v31s1/CPPv31s1p021.pdf> Dr. Stuart lists ways of conducting successful campaigns. I summarize these:

- aim for improvements in the lives of people with mental disorders and their families;
- involve consumers and families in all aspects of system development;
- accept that education changes literacy but changes in behaviour are difficult to achieve;
- programs should be modest in scope;

¹ From Heather Stuart’s chapter in the 2008 book, ***Understanding the Stigma of Mental Illness: Theory and Interventions*** by Arboleda Florez and Santoris.



- programs should be targeted to specific populations;
- accumulate small successes;
- use the media as allies in the process;
- build on the work of others and of best practice models.

Let's Ignore the Illness

A recent review by the Queensland Alliance of Mental Illness and Psychiatric Disability (Australia) <http://www.qldalliance.org.au/news/items/314431-upload-00004.pdf> entitled **From Discrimination to Social Inclusion** was recently presented by the consultant to the project, Neasa Martin, at the national conference of the Schizophrenia Society of Canada. The review shares some of the ideas listed in the previous section but one of the Recommendations listed (page 8) says:

***Mental health problems are best framed as part of our shared humanity.** Mental health problems are an understandable response to a unique set of circumstances and not purely as biomedical, genetically based, illnesses, or a diseased state of brain.*

In Chapter 2 a “disability inclusion model” is proposed.

Disability is seen as: a result of the socially imposed barriers and prejudices imposed from outside and faced by the individual that limit their citizenship and full participation in society. It is not the consequence of individual limitation (illness).

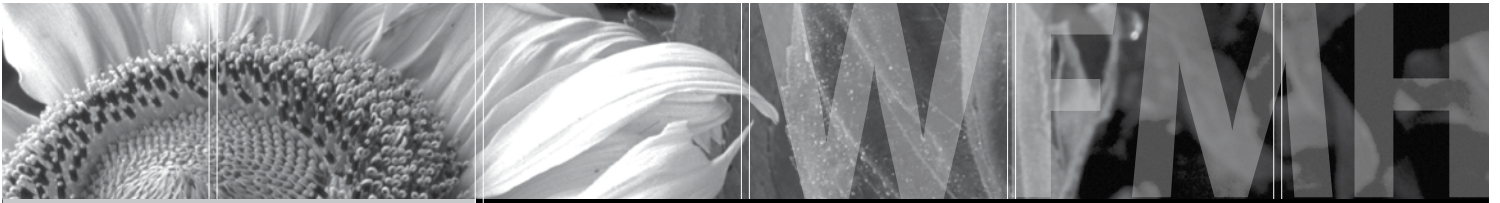
In the next chapter under the subtitle “**Framing matters ‘illness like any other’ is not the approach**” a subsection called “The research suggests” states:

Psychiatric labeling (diagnosis), hospitalization, use of psychotropic medications and being treated by a psychiatrist all increase public fear, desire for social distance and tolerance of ‘risk containment’ through coercive treatment. These treatment elements need to be de-emphasized in public education.

The latter is a pretty definitive statement for which the paper offers no references to back it up.

A New Zealand study cited in the text is *The differential effectiveness of psychosocial and biogenetic causal explanations in reducing negative attitudes toward mental illness* by Walker and Read (2002). It states that “the ‘medical model’ approach significantly increased perceptions of dangerousness and unpredictability”. Following the psychosocial explanation there was a slight but statistically insignificant improvement

Mental health problems are an understandable response to a unique set of circumstances and not purely as biomedical, genetically based, illnesses, or a diseased state of brain.



in attitudes. The absence of a statistically significant difference means that there is no difference – it is **not proven** that the psychosocial approach is better.

The last study cited in this section, also by Read, concluded:

It is recommended that destigmatization programmes consider abandoning efforts to promulgate illness-based explanations and focus instead on increasing contact with and exposure to users of mental health services.”

A study from the World Psychiatric Association schizophrenia campaign portrays the belief that schizophrenia is a debilitating disease as sophisticated and knowledgeable

Note that it is recommended that “abandoning efforts” should be **considered** rather than that they should actually be abandoned.

The Queensland review also references *Prejudice and schizophrenia: a review of the ‘mental illness is an illness like any other’ approach* also by Read. This paper is very telling. The anti-medical model bias is strong as Read explains that “A study from the World Psychiatric Association schizophrenia campaign portrays the **belief** that schizophrenia is a debilitating **disease** as sophisticated and knowledgeable. Another study actually used mental illness is an illness like any other as an item measuring a liberal, knowledgeable, benevolent, supportive orientation toward the mentally ill” (bolding by this author).

The biased agenda of the review’s author is found in this statement:

“For example, a review of recent research concludes that symptoms considered indicative of psychosis and schizophrenia, particularly hallucinations, are at least as strongly related to childhood abuse and neglect as many other mental health problems. Recent large-scale general population studies indicate the relationship is a causal one, with a dose-effect (140). Many other psychosocial factors have also been found to contribute to the etiology of schizophrenia and psychosis (122, 139).”

This is from Page 313 of the journal and the numbers are the references in the footnotes to prove this assertion. Reference 140 is to another paper that he, himself, wrote. He quotes himself to prove himself.

Reference 139 is to an article he wrote with the late Dr. Loren Mosher, a highly controversial psychiatrist who was dismissed by the National Institute for Mental Health. According to his obituary in the Washington Post, “he advocated a largely drug-free treatment regimen for schizophrenics” and “his position was based on a view that schizophrenics are tormented souls who needed emotionally nourishing environments in which to recover.



Marvin Ross is a Canadian medical writer and publisher. His book relevant to this article is *Schizophrenia: Medicine's Mystery – Society's Shame on the stigmatizing by medical professionals towards people with schizophrenia*. He is pleased that the book he publishes *After Her Brain Broke: Helping My Daughter Recover Her Sanity* by Susan Inman is getting good reviews everywhere even though its title has been criticized for increasing stigma by using the word "broken". His next book coming in September will also draw criticism because the author (who does have schizophrenia) wants the title to be *My Schizophrenic Life: The Road to Recovery From Mental Illness*.

He said drugs were almost always unnecessary, except in the event of a violent or suicidal episode." Reference 122 was written by a co-author of reference 139.

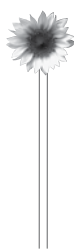
Finding a Solution

Problems, however, with using the 'education about the illness' approach to anti-stigma do exist. Studies published in the *Canadian Journal Of Psychiatry* in 2003 from the WPA Open the Doors studies in Germany and Canada did find that perceiving the mentally ill as unpredictable and dangerous was the main stigmatizing feature reinforced by education. Perhaps, after this finding, the WPA has modified its education to show that the majority of those with mental illness have no tendency to violence. *Open the Doors* is endeavoring to explain and reduce stigma, the doors are opening but there is much more to be done. Abandoning current programs and methods when much groundwork has been done and just when we are beginning to learn what works and what doesn't would be foolish.

Rethink Mental Illness, the UK charity, says on its website:

In order to change negative attitudes to mental illness, the public needs to be aware of what it means, that it takes strength and courage to live with, that it can be treated and managed, and that stereotypes of violence and mental incapacity are not accurate.

Another way forward, as Dr. Arboleda-Florez concluded in his editorial summation to the 2003 *Open the Doors* study is, rather than de-emphasizing education about illness, as the Queensland Alliance and others suggest, that the best approach is to limit the possibilities for people to become violent via proper and timely treatment and management of their symptoms and preventing social situations that might lead to contextual violence; he writes that this could be the single most important way to combat stigma.

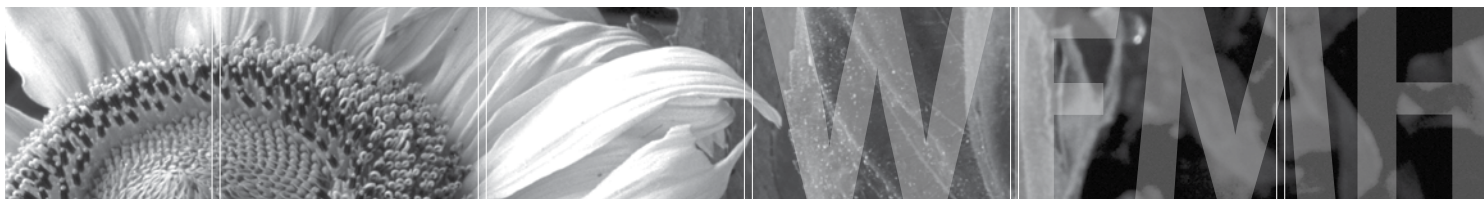


Après le décès d'un voyageur

Après le décès d'un voyageur *poussé contre un RER*, le psychiatre Yann Hodé revient sur ces accidents qui impliquent des patients souffrant de schizophrénie.

Ce décès était-il évitable ?

Les médias ont précisé que le "*pousseur*" souffrait d'une schizophrénie et qu'il avait arrêté son traitement. Sa mère avait signalé à plusieurs reprises sa dangerosité. Il y aurait donc eu, en théorie, des possibilités



Le respect de la liberté individuelle entraîne une réticence, légitime, à prendre des mesures pouvant paraître comme liberticides.

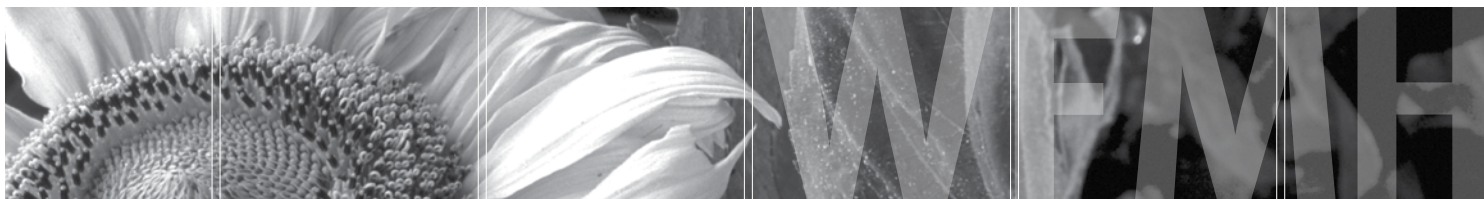
de prévention. En pratique, des événements de ce type sont rapportés presque annuellement dans la presse, et pourtant de nombreuses familles continuent à se plaindre de ne pas trouver d'aide lorsque leur proche malade a un comportement dangereux. Dans ce domaine, chacun essaie de se défaire sur l'autre. Les services de police ou de gendarmerie lorsqu'ils sont alertés disent que cela dépend de la psychiatrie, la psychiatrie répond souvent qu'elle ne peut pas aller chercher une personne, qu'il faut qu'on l'amène à l'hôpital pour qu'elle puisse agir. Les médecins généralistes ne sont pas toujours bien formés à analyser la dangerosité de certaines situations et ils se plaignent d'être parfois très seuls face à des services hospitaliers qui ont quelques peines à les entendre. Des drames comme *celui du RER parisien*, pourtant, n'ont rien d'inéluctable.

Pourquoi ne pas avoir hospitalisé cet homme, de force si nécessaire, avant que le pire se produise ?

Le respect de la liberté individuelle entraîne une réticence, légitime, à prendre des mesures pouvant paraître comme liberticides. Nous avons plus à craindre un contrôle excessif de toute déviance comportementale que le risque - rare - d'agressions graves par des personnes malades. L'influence salutaire de la réflexion de Foucault sur le contrôle que la société veut exercer sur des individus nous a appris à être prudent face à des mesures de pseudo bon sens qui procéderaient d'une logique opprimante pour l'individu. En même temps, ne pourrait-on pas intervenir plus souvent de façon préventive sans pour autant prendre un risque d'atteinte à nos libertés ? Entre les positions sécuritaires, inadaptées, et les positions non interventionnistes, dogmatiques, n'y aurait-il pas la place pour des positions plus humbles et ouvertes au dialogue, pour la recherche d'une meilleure prévention possible dans le respect de la protection de la liberté des individus ? C'est ce que pensent de nombreuses familles de malades. Elles sont confrontées au quotidien à des anomalies de comportement tellement manifestes de leur proche qu'elles ne comprennent pas les réticences auxquelles elles font face pour le faire soigner contre sa volonté.

Pourquoi les familles ne sont-elles pas écoutées ?

Leur parole est souvent suspecte car elle est jugée partielle par les équipes médicales. Ces dernières ont un point de vue certainement moins affectif mais non moins partial, car elles ne voient pas au quotidien la réalité des troubles du malade. Sans en faire une généralité, de nombreux professionnels de la psychiatrie ont tendance à ne pas écouter ce que

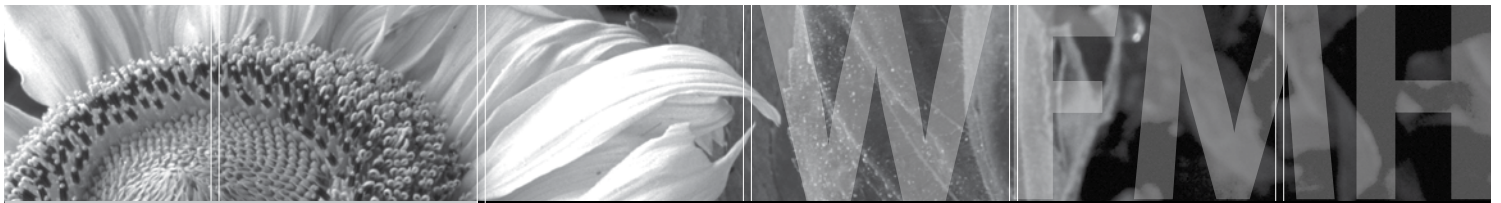


disent les familles. Dans une étude récente réalisée auprès de 33 parents participant à un programme psychoéducatif pour soutenir leur proche souffrant de schizophrénie, 40% d'entre eux se disaient plutôt insatisfaits de leur demande d'aide auprès des médecins et 36% insatisfaits de la communication avec le médecin qui suit leur proche. Et même si cet échantillonnage n'était pas représentatif, les associations de familles de malades rapportent suffisamment de cas de difficultés de communication des familles avec la psychiatrie pour penser que ces situations ne sont pas rares. Cette difficulté à prendre en compte les familles et à les écouter contribue à une mauvaise évaluation des risques réels liés à l'état du malade. Notre médecine est une médecine qui donne la primauté à l'individu dans une relation duelle médecin-malade et c'est un mode de fonctionnement que la grande majorité d'entre nous ne voudrait pas voir remise en cause. Quelque soient les relations que nous pouvons entretenir avec notre famille, nous préférons avoir la maîtrise de la façon dont nous voulons ou non l'associer dans la connaissance de notre état de santé et dans les décisions afférentes. Dans cette logique, la famille est habituellement ignorée du médecin.

Peut-on espérer un changement ?

De plus en plus de médecins sont aujourd'hui attentifs aux appels de détresse des familles. Des efforts sont encore à faire mais c'est l'ensemble de la société qui doit changer. Que chacun ouvre ses yeux, son esprit et son coeur, qu'il ne reste pas sur ses préjugés et ses connaissances anciennes alors que la compréhension des maladies mentales a été profondément changée en à peine plus de deux décennies. Souvent perçues à tort comme des maladies de l'âme plutôt que comme des maladies du cerveau, elles posent des questions éthiques difficiles. Les malades souffrant de schizophrénie représentent 1% de la population (20 personnes dans un village de 2000 habitants), mais un pourcentage dix fois supérieur des personnes incarcérées et des personnes en situation de grande précarité. Rappelons-le, les maladies mentales ne sont pas rares, elles n'arrivent pas qu'aux autres, elles ne sont pas un échec personnel, beaucoup se soignent très bien, et elles n'ont rien d'infamant. Encore faut-il avoir la curiosité de s'informer sur elles, sur les progrès des neurosciences. C'est une bonne façon de contribuer à une société plus humaine.

***Le Dr Yann Hodé** est psychiatre à l'hôpital de Rouffach (Haut-Rhin).*



News from the Groups

News from SANE Australia

Money and Mental Illness

SANE Australia has recently researched the topic of Money and Mental Illness. A sample of 371 people completed a questionnaire anonymously via the SANE website in April and May of 2009. A PDF version is available at www.sane.org. Below is the four-point summary of the survey:

- The majority of people with a mental illness live on or below average incomes, with one third surviving on less than Aus \$20,000 a year.
- The cost of living with a mental illness is high, with many expenses not fully met by Medicare or social security payments.
- The smoking rate among people with a mental illness is very high, yet they often cannot afford quitting aids such as NRT, which are not subsidised.
- People with mental illness often have to choose between going without medical treatment or without essentials such as food.

Getting help early

A major new social advertising campaign from SANE uses TV, radio, print and the Internet to promote understanding of the early signs of mental illness, and highlights the importance of getting help for those affected.

. . 'Friends and family are often the first people to notice the changes in behaviour or thinking that can be early signs of mental illness. SANE encourages people to have the confidence to act on their concerns as soon as possible. . . ' says Barbara Hocking, SANE Executive Director.

3 Family organizations change their names

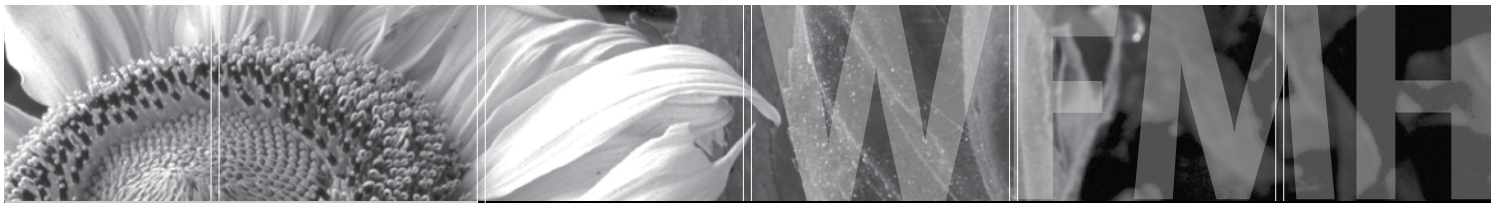
Supporting Families in Mental Illness – New Zealand - is the new name for the Schizophrenia Fellowship New Zealand. The news comes to us from the new and glossy magazine of Supporting Families in Mental Illness: ISEA (Information . Support . Education . Advocacy).

Website: www.supportingfamiliesnz.org.nz/

The name change is an issue that had been debated for many years. The desire to have a name that reflects our purpose today and into the future meant that we would have to say goodbye to the original name that was created by our organization's founders. . .

We embarked on identifying a new name that clearly reflected the organization's purpose and one that left no room for confusion when it came to stating our priority. . .

Friends and family are often the first people to notice the changes in behaviour or thinking that can be early signs of mental illness



Center News • 2nd Quarter 2010

Today Supporting Families through our 21 branches continues to provide services direct to families. The national office is responsible for advocating at a national level for better services for families affected by mental illness, offering policy advice to Government, ministries and other key stakeholders. National office is also responsible for developing information and education resources that can be used by families, DHBs [District Health Boards], government departments, clinicians, mental health professionals and other NGOs.

Shine – Supporting People Affected by Mental Ill Health, the new name for Schizophrenia Ireland, reflects a positive and inclusive image, according to Director John Saunders. The organization wants the name to be positive and non stigmatizing. “We also wanted to encourage people to focus on their experiences, and the potential for recovery”, he said. The organization will continue its current activities, described on its website: <http://www.shineonline.ie>

“We also wanted to encourage people to focus on their experiences, and the potential for recovery”

To promote the development of parallel self help groups for people with psychosis and their family members and carers.

To empower people with psychosis and enduring mental illness and their family members and carers through support, individual advocacy, information and education.

To promote the right of all those affected by psychosis and enduring mental illness to person-centred and appropriate services, which will support the process and goal of recovery.

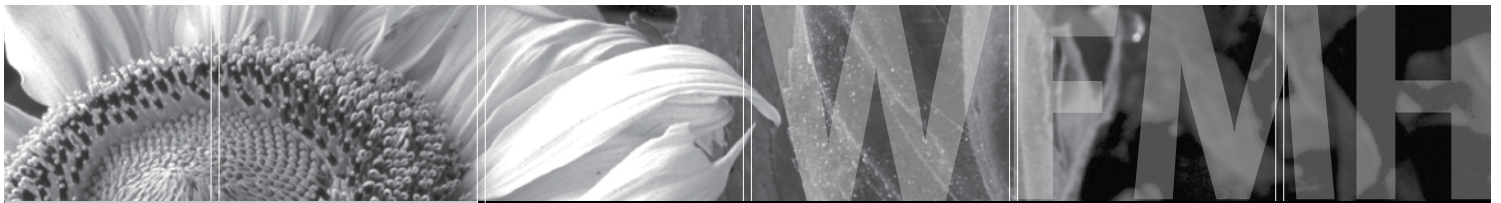
To engage in public awareness activities aimed at challenging discrimination and stigma, and advocating for the rights and needs of all those affected by psychosis and enduring mental illness.

To campaign on behalf of all those affected by enduring mental illness to influence policy changes in the provision of mental healthcare services.

Caring4carers is a UK organization founded by **Jeffrey Breslaw** in 2000 under the name “Mencare”. The organization educates and informs families of those with psychiatric conditions through a course of education. Jeffrey Breslaw also aims to educate young psychiatrists by involving them in the program.

Caring4carers uses a version of the educational program “Supportive Family Training” developed by **Sheila LeGacy** in Syracuse, New York.

Reach them at their new name and website: www.caring4carers.org.uk/



Self Help Group “Cuenta Conmigo” (Count on me) in Nicaragua

By Karla Liseth Alaniz Matus, member of the board of directors of CC.

He has suffered from a psychotic disorder for some years. I had always been uneasy about how and why this had happened and what possibility there was of recuperation, but my questions to him came to nothing.

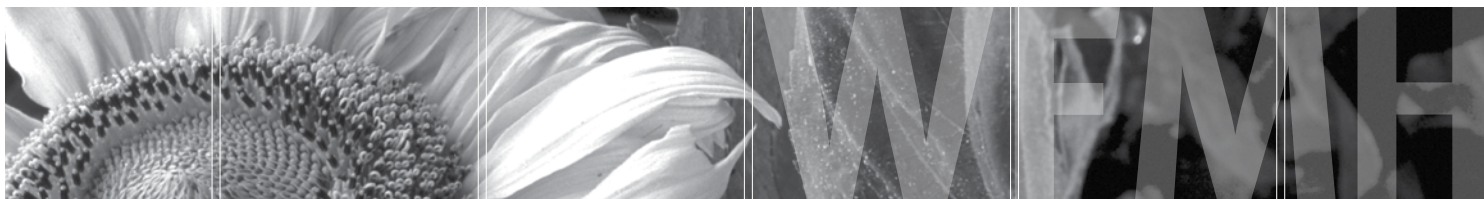
One day I went into the policlinic of Matagalpa, Nicaragua, in order to collect my father's medications. He has suffered from a psychotic disorder for some years. I had always been uneasy about how and why this had happened and what possibility there was of recuperation, but my questions to him came to nothing. So I decided to study psychology at a state university. Years passed when a university lecturer said that a group was being established for the families of those with psychotic disorders.

This was the first time that I heard of Cuenta Conmigo. Then, the same day, as I was collecting the medications, I saw a poster which invited people to come to the General assembly of families in Cuenta Conmigo. I decided to take part. I learned about their activities, such as information meetings, occupational workshops, recreation, workshops for adolescents, and home visits to share psychoeducation with families. There were two or three activities a month while home visits went on throughout the week.

The self-help group began to grow with the assistance of a Dutch NGO (non-government organization) committee Mano Vuelta and the cooperation of volunteer psychiatric nurses from Holland. They had continued to follow the activities of Cuenta Conmigo - the only group with this focus in the northern zone of the country. The work grows because of the great demand for assistance in the group and the need to meet the challenges, particularly the need for independence which is the goal for Cuenta Conmigo. At present there is a board of directors, an administrator, someone on promotions, help from outside volunteers and Nicaraguan university student volunteers - thanks to their impact on the project, the group has been strengthened.

We have a proper office and are thinking, for the future, about being self-sustaining we have worked on the development of a laundromat project. In Matagalpa there is a demand for this service but we have not as yet found a suitable location where this could be carried on by stable consumers or families. Also we are working on the official legalization and registration of the organization which will give us greater authority in front of those like the Minister of Health. This will enable us to form alliances with the other associations working with disabled persons in order to lobby for benefits. Such status will strengthen our ability to hold conferences in which families and consumers will be able to acquire knowledge, always remembering that our psychoeducation programs are the primary objective of Cuenta Conmigo Matagalpa.

Translated from the Spanish version on page 21.



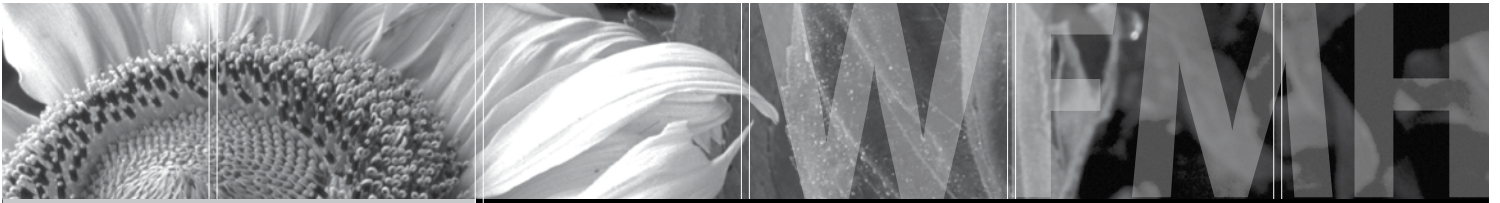
El grupo de autoayuda Cuenta Conmigo en Nicaragua

Un artículo por Karla Liseth Alaniz Matus, miembro de la Junta Directiva de Cuenta Conmigo

Un día me encontraba en el policlínico de Matagalpa (Nicaragua) para retirar los medicamentos de mi padre quien sufre un trastorno psicótico desde hace algún tiempo. Siempre tuve la inquietud de saber cómo y porque había sucedido esto, que posibilidades tenía de recuperarse pero las respuestas eran pocas o mejor dicho ninguna, entonces decidí estudiar psicología en una universidad estatal. Pasaron los años y fue entonces cuando una maestra de la carrera comento que se estaba formando un grupo de autoayuda de familiares de personas con trastornos psicóticos. Esa fue la primera vez que escuchaba de Cuenta Conmigo. Luego, en el día en que retiraba el medicamento vi un papel en el que invitaban a la Asamblea General de familiares en Cuenta Conmigo. Decidí asistir y me informaron de sus actividades como reuniones de compartir para familiares, reuniones informativas, talleres ocupacionales, actividades recreativas, talleres para adolescentes y visitas domiciliarias para brindar psicoeducación a las familias. Las actividades se realizan continuamente 2 o 3 actividades en el mes, las visitas domiciliarias durante todo la semana.

El grupo de autoayuda empezó a crecer con el apoyo del ONG Comité Mano Vuelta, la ayuda de un ONG de Holanda y la cooperación de enfermeros psiquiátricos voluntarios de Holanda. He seguido desde cerca las actividades de Cuenta Conmigo siendo este el único grupo con este enfoque en la zona norte del país. El trabajo crece por la gran demanda de la asistencia a este grupo y las exigencias se convierten en un reto, la independencia que hoy en día es la meta para Cuenta Conmigo. Ahora se trabaja con una Junta Directiva, administradora, promotora, apoyo de voluntarios extranjeros y nicaragüenses (estudiantes voluntarios de universidades) esto gracias a la incidencia del proyecto, el grupo se fortalece ahora, ya contamos con una oficina propia y pensando en el futuro y la auto sostenibilidad hemos trabajado en un proyecto de lavandería pues en Matagalpa existe la demanda de este servicio pero no hay un lugar para este funcionaria y sería atendido por usuarios estables o familiares. También estamos trabajando en el proceso de legalización que permitirá legalizar la asociación y hacer mejor incidencia ante autoridades como el Ministerio de Salud (MINSA), unirse con las otros asociaciones que trabajan con personas con discapacidad, hacer demandas y obtener beneficios para los familiares y usuarios, participar en los congresos para adquirir conocimientos que luego serán transmitido a los usuarios y familiares del proyecto sin olvidar que la psicoeducacion es el objetivo primordial del proyecto Cuenta Conmigo Matagalpa.

Pullouts



Organizations of Interest with their websites

Eufami – the European Federation of Associations of Families of People with Mental Illness – has an interesting website. Of particular interest recently has been the conference entitled “The Forgotten Children”. Here is a small excerpt from the conference declaration:

Delegates from 25 countries across Europe confirm their support for this Declaration following their participation at the EUFAMI Conference held in Vilnius, Lithuania on 26th and 27th November 2009.

Children of parents with mental illness bear serious burdens which they cannot be expected to carry on their own. They are vulnerable to long term emotional and behavioural problems and do not normally have a say in how they are treated. They and their families therefore need regular support from health, social and school staff professionals as well as an understanding of their situation within their local communities.

The Eufami website is: www.eufami.org/

SANE UK is a charity that both lobbies for and supports those with psychiatric disorders in the UK. Some years ago SANE started SANEline, a national out-of hours telephone helpline offering emotional support and information for people affected by mental health problems. Their website advises:

Whether you are worried about your own mental health, or you are a concerned family member, friend, acquaintance or professional, don't be afraid to call. SANEline receives thousands of calls every year from people like you. Whether you are seeking information or the opportunity to share your feelings with someone, SANEline aims to give you the time and space to explore your situation, without judging or telling you what to do.

Children of parents with mental illness bear serious burdens which they cannot be expected to carry on their own.