



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

Center News • 1st Quarter 2010

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FIRST ISSUE OF CENTER NEWS

Welcome to the first issue of **Center News**, the news magazine of the WFMH Center for Family and Consumer Support and Advocacy. We invite all WFMH members and those coming to this section of the website to submit worthy columns, articles and news items (with photos where possible) that will inspire, motivate, support and advocate on behalf of those with psychiatric disorders and their families.

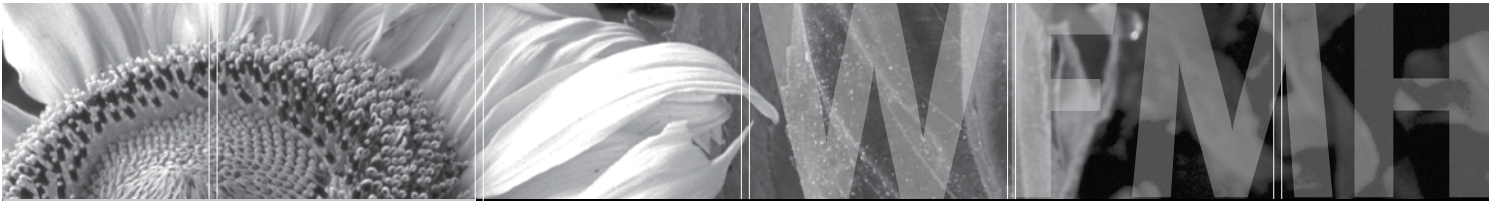
The Center has emerged as part of the merger between WFMH and WFSAD (the World Fellowship for Schizophrenia and Allied Disorders). Center News looks forward to being a web publication in the spirit of the WFSAD Newsletter which many members have enjoyed over many years. (You can still see past issues of this at www.world-schizophrenia.org under Publications/ Newsletters.)

In this issue we bring you a variety of information coming to us from many sources. *Expressions* is a section for poetry. *Miscellany* is a section for short news items or interesting sayings. *Books and Films* will review some of the many books that are published about mental health from the consumer/ family point of view, as well as news of new films or videos that readers can access. These will be regular features. In this issue the poem 'Metas' is in Spanish.

In future issues we hope to continue the practice of having some submissions in Spanish or in both English and Spanish with the click of your mouse. In this issue we have an article that originated in French. It is the winning article, by Estelle Saget, of the European Union Health Prize for Journalists. We publish the translation as well as the link to the French version.

We hope you will enjoy reading this issue.

Diane Froggatt



European Union gives two prizes for articles about schizophrenia

Winners of the EU Health Journalism Prize announced at an award ceremony in Brussels

At an award ceremony held in Brussels recently, the European Commissioner for Health, Androulla Vassiliou, announced the three winners of the first **EU Health Prize for Journalists**. French Journalist **Estelle Saget**, author of the article “Schizophrenia explained to family and friends” for ‘L’Express’ won the first prize. You may read the article in French here: http://ec.europa.eu/health-eu/doc/jp_fr_art_fr.pdf

Lithuanian journalist, Audrė Srėbaliėnė, author of an article on donating bone marrow for ‘Ekstra’, in second place, and Romanian journalist, Emilia Chiscop, writing in ‘Ziarul de Iasi’ in third place, for her article on a young doctor coping with schizophrenia. The aim of this prize, launched in February of this year, is to award high quality journalism that help citizens better understand health issues, especially those related to the ‘Europe for Patients’ campaign.

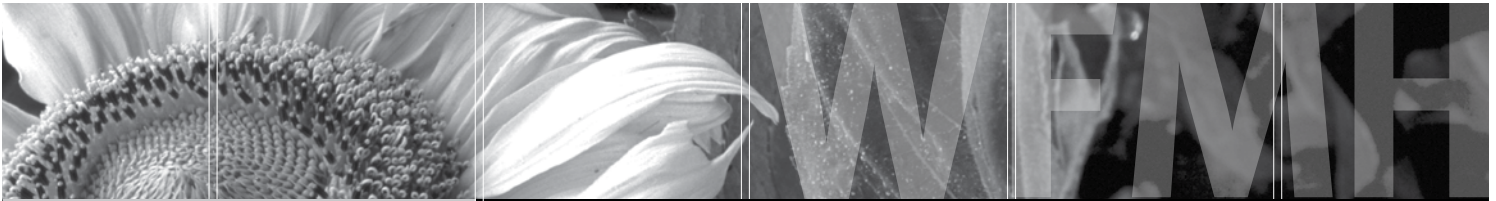
Over 300 journalists from all 27 countries of the European Union submitted a total of 468 articles. National juries selected a finalist from each member state. The 27 short listed articles deal with a broad range of subjects such as patient safety, organ donation and transplantation, cross-border healthcare, mental health, rare diseases and cancer.

Androulla Vassiliou, EU Commissioner for Health said: “The quality of the winning articles has exceeded my expectations. It has been a delight for me to read such interesting and informative articles on the vital subject of health. The winning articles raise awareness and destigmatise health issues such as mental illness and organ donation and give them a human face.”

For more information about the EU health prize for journalists and to read the winning articles and the short listed articles, please refer to the Europe for patients’ website: http://ec.europa.eu/health-eu/europe_for_patients/index_en.htm

Saget’s article talks about schizophrenia and describes the ProFamille Program of psychoeducation. The program originally came from Quebec and has helped so many families in French speaking countries. It has been improved year after year in France and in Switzerland and is now used by many teams (families trained in this program or mental health professionals) in Switzerland, Belgium, Morocco and France.

“The quality of the winning articles has exceeded my expectations. It has been a delight for me to read such interesting and informative articles on the vital subject of health. The winning articles raise awareness and destigmatise health issues such as mental illness and organ donation and give them a human face.”



We are grateful to Monique Pasche Member of the Committee of the organization of French-speaking families of patients with schizophrenia in Berne, Switzerland for the translation of the article. Monique is Coordinator of the French-speaking Network of people delivering the psychoeducational program “Profamille”. She is the mother of a son with schizophrenia. With her permission we reproduce the English version of this article:

Saget’s Winning article

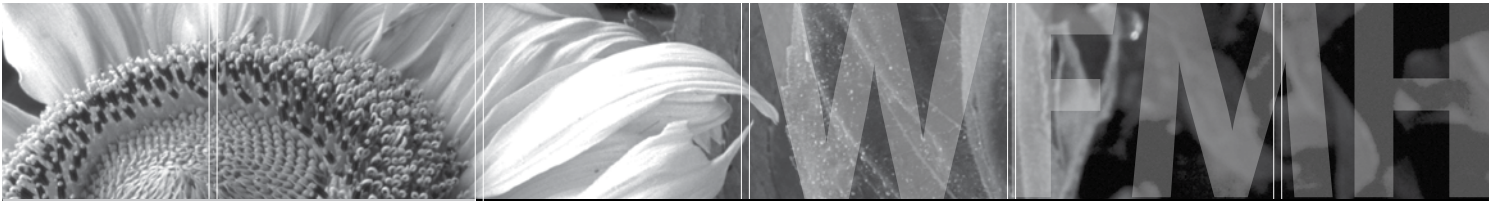
Schizophrenia Explained to Family and Friends

A recent stabbing has re-opened the debate on schizophrenia. But how can we fight it more successfully? L’Express magazine visited a psychiatric hospital in Alsace that offers courses for patients’ families. Doctors say that the programme – which offers support and advice – makes patients less likely to suffer a relapse.

Night has just fallen over the park surrounding the Rouffach psychiatric hospital (in the department of Upper-Rhine). Through the stately trees, you can see the squat silhouettes of pavilions in the dark, opulent buildings that bring to mind spas from the early 1900s. One of them is pavilion No 12, whose tall, lit-up windows make it look like a ballroom. But at this time of day, all the patients have gone home. The 5p.m. shuttle has taken them back to the town of Mulhouse, 30 minutes away. For schizophrenic patients, No 12 is halfway to freedom: the doors are not locked, like at No 24, and they only have to be there during the day. So who is still there then, on a Thursday evening in November, in the common rooms? It is the nurses, who are giving a rather unique evening course.

Every Thursday, friends and family of schizophrenic patients come to learn how to react to the disconcerting behaviour caused by this mental illness. For three months, they attend a programme called Profamille, imported from Canada. The current group has approximately ten participants, including one father and several mothers of young patients (schizophrenia generally appears when the patient is between 15 and 25 years of age) and the wife of a patient in his late 30s. All of them are dealing with the stigma and prejudice associated with schizophrenia – despite the fact that it is widespread, affecting up to 1% of the French population.

Every Thursday, friends and family of schizophrenic patients come to learn how to react to the disconcerting behaviour caused by this mental illness.



The advice? Give your emotions a name

Their common predicament has brought together individuals from very different social backgrounds. Cook, airport security guard, teacher, doctor... they all form a small, tight-knit community that meets on Thursday evenings in pavilion 12. Sitting in armchairs arranged in a semi-circle, books open on their knees, they gnaw at their pencils like schoolchildren, with furrowed brows. On the coffee table, a computer plays dissonant symphony music. The participants are instructed to write down what they feel. "Worry," writes one. "Fear," notes another. The exercise continues with a hard rock song, then the soundtrack of a humorous cartoon and, finally, a few notes from a zither. The teacher returns to where he was, standing before the group. "What you've just done is learn to recognise and give a name to your emotions", explains Raoul Krychowski, a nurse who has been involved in the programme since it began in 1999. "Now you'll be able to do the same with your loved ones, who because of their illness can't accurately interpret other people's reactions. By saying out loud what you're feeling – joy or anger, for example – you help them figure out where you're coming from and reduce the risks of misunderstanding."

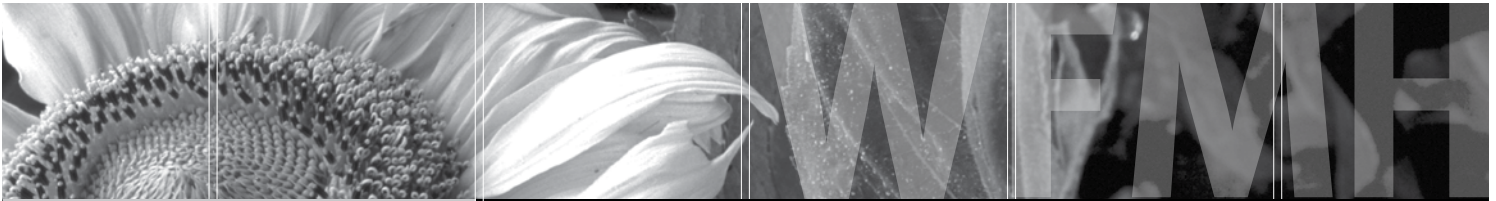
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What is going on at Rouffach hospital amounts to much more than just a discussion group along the lines of Alcoholics Anonymous. The participants support each other, of course – for instance when one of their children starts using cannabis again (which has been shown to cause delusions) or has to return to hospital because he or she can no longer communicate coherently. One mother opens up during the dinner break: "My son refuses to take his medication. He says it makes him feel like his head's going to explode," she says, wearily. "Some days, he thinks he's being poisoned." The woman next to her lays a sympathetic hand on hers: "This morning, I suggested to Lucas that he should start taking his meds again, without pushing it," she explained. "And it worked."

No need to spell things out here

Nearby, another mother confesses her feeling of helplessness: "I fear the worst for Nicolas. When I come home with his young brother, I always go in first." There is no need for her to explain it's because she fears he may have hanged himself. Here, things do not need to be spelled out.

This kind of moral support is a beneficial side effect, but the primary aim of the training is to help families face up to schizophrenia, which causes hallucinations and makes it difficult for victims to organise their thoughts. The illness has nothing to do with split personalities, as is often believed.



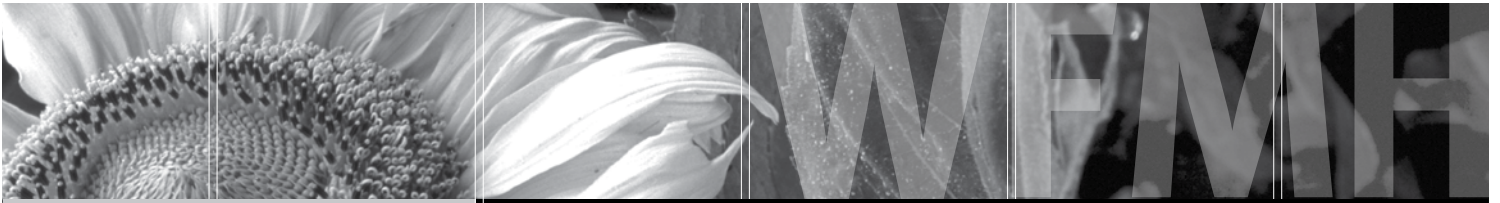
“People who suffer from what we call schizophrenia are just like us. They’re not impossible to understand. Not some kind of weird specimens whose lives can be understood by notions of them as inhabited by something completely alien.”

Over 13 sessions, participants learn about this complex pathology and ways to cope. The method mixes personal development and behavioural therapies – ranging from breathing exercises to reduce stress to clearing up mis-conceptions. “It’s not a lack of love that causes schizophrenia. And love won’t cure it, either,” interjects the teacher, as parents are discussing.

So does the programme work? The scientists say it does. The team from Alsace has assessed its programme and just published the results in a specialised review. Of the 42 study participants, 18 were suffering from depression at the beginning of the sessions – a large percentage, explained by the burden that schizophrenia places on patients’ close relations. By the end of the sessions, seven had come out of their depression. But Profamille does not just improve quality of life for people indirectly affected by schizophrenia. It helps patients too. International studies show that patients whose family and friends receive counselling relapse less often. In fact, relapse is four times less likely in the year following counselling.

In pavilion 12, a sticker on a door is all that marks the office of the programme leader, Dr Yann Hodé. Even though the programme is offered in only a few cities in France, this 47-year-old psychiatrist with a salt-and-pepper beard is determined it should set an example. “When it comes to treating schizophrenia, we need to be looking for ways to improve that don’t involve medication,” he explains. “Antipsychotics remain an essential part of treatment, but they have shown their limits.” According to Dr Hodé, the mere fact of educating families helps patients to be better understood and accepted as they are – to do better in a word. His plea mirrors that of another psychiatrist, Alain Bottéro, who challenges his peers in a scathing book, “Un autre regard sur la schizophrénie” (*A different approach to schizophrenia*, published by Odile Jacob). “Patients get too much medication and not enough attention to help face their internal struggles...,” he writes. “If we don’t make an effort to understand them and show empathy, their condition worsens.” He goes even further. “People who suffer from what we call schizophrenia are just like us. They’re not impossible to understand. Not some kind of weird specimens whose lives can be understood by notions of them as inhabited by something completely alien. They’re men and women who are trying to cope with the same difficulties we are, but with an extra burden that we would do well to keep in mind.”

People like us. Hélène – whose boyfriend fell ill in 2002 – could not have put it better. The 39-year-old runs a clothing shop in Mulhouse and took Profamille training last year. Tall and slender, with fine features and expressive eyes, she welcomes us today to their simple, well-looked-after ground-floor apartment in a quiet suburb of the Alsatian town. She



explains that before meeting Thierry, when she was 21, she'd gone out with a few unserious "laddish" guys. "He was different, not a loudmouth" she recollects, eyes shin-ing. "Right away, I fell for his reserved side, his sensitivity, how serious he was about his work".

Treatment has spaced out attacks

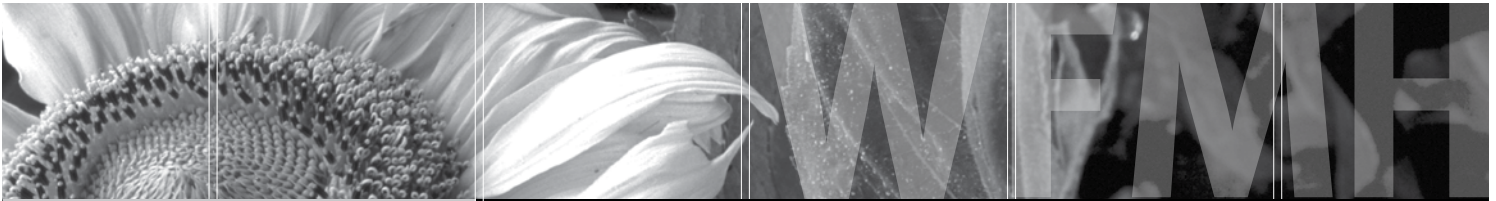
Today Thierry is 37. Every two weeks he receives an injection of antipsychotics and every day takes 10 pills to counter the side effects of the treatment and stave off depression. He has just been put on disability, and he panics when H el ene leaves him alone too long at home. "The illness has changed his behaviour, but not his personality," she continues. "I've never considered leaving him." The couple has begun having sex again, which they had stopped. "I let him make the first move," H el ene explains. "I don't want that to be a source of stress for him."

Then we see Thierry passing in front of the kitchen window, walking with long strides, smoking a cigarette. A taxi has just dropped him off at the corner, after a day at pavilion 12. He sits down at the table, his face set, behind thin glasses, waiting for our questions. Over the past two days, the lead story on the TV news has been the fatal stabbing of a student by a schizophrenic in Grenoble. Had he heard? "Of course," he replies dispassionately, before giving a precise account of the incident. What is his take on it? "I am schizophrenic myself," he begins. "So stories like that scare me... I wonder if I'd be capable of doing something like that. I don't think so," he says before adding, as if to reassure himself: "I still know what I'm doing." H el ene doesn't bat an eye. "Thierry's not violent," she smiles. Treatment has not got rid of his hallucinations, but it has made them less frequent. And most importantly, they are over quickly, now that H el ene – thanks to the Profamille sessions – knows how to react calmly.

Every time, his hallucinations follow the same script, with slight variations: sitting on the living room couch, Thierry thinks he sees his father in the room, either in the flesh or on the TV screen. Actually, his father died suddenly of a heart attack in 2002. It was just a few months later that Thierry showed the first signs of schizophrenia. And here he is – six years later – face to face with his dead father, who sometimes says to him, "Don't worry, everything's gonna work out" – but who can be threatening too, as on the terrifying day when he barked, "You'd be better off just ending it all!"

Last time, though, H el ene did not let her father-in-law do all the talking. The couple had just settled down on the couch when Thierry said his father was with them.

"The illness has changed his behaviour, but not his personality..."



“Where exactly?” asked H  l  ne.

“Right in front of us, sitting on the coffee table.”

She got up and sat down just where Thierry had said.

“Here?” she asked.

“You’ve got to move, H  l  ne, you’re bothering him! He doesn’t want you sitting next to him!”

“Thierry, you’ve got to listen to me and not your father. Do that breathing exercise you know with me . Come on, I’ll I count. One, two, three...”

After inhaling and exhaling 20 times, H  l  ne manages to distract Thierry’s attention. The hallucination has disappeared, and they can both go about their business. He goes to do something on the web. She has a look at their budget, which is tight, but there might just be enough for a new car. Today, they can make plans again. They are waiting for the winter sales to buy anoraks and take a week’s holiday somew-here with snow. Never mind the schizophrenia.

Schizophrenics have difficulty working, relating to others and taking care of themselves. Symptoms must continue for at least six months for a patient to be diagnosed as schizo-phrenic.

An illness with no easy definition

The definition of schizophrenia is still quite vague and its causes are poorly understood. Currently, patients exhibiting several of the following symptoms may be diagnosed as schizophrenic:

- delirium
- hallucinations (hearing voices or having visions)
- incoherent speech
- disorganised behaviour
- apathy, passivity, absence of emotional reactions.

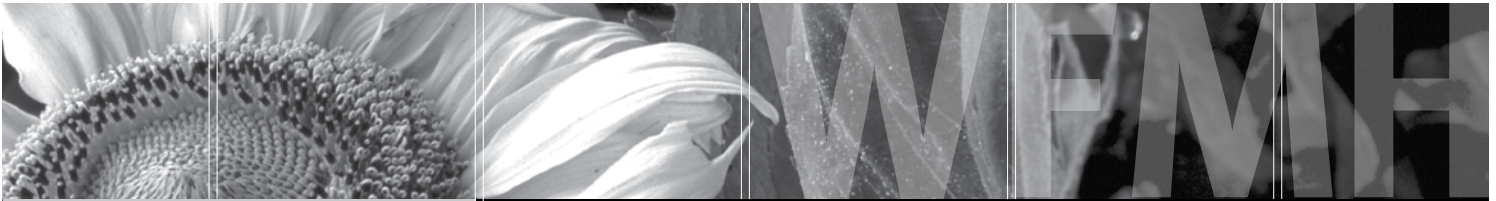
Schizophrenics have difficulty working, relating to others and taking care of themselves. Symptoms must continue for at least six months for a patient to be diagnosed as schizo-phrenic.

¹ The first names of the persons portrayed in this article have been changed.

² Rouffach, Sarreguemines, Nancy, Grenoble, Caen, Marseilles (Saint-Marguerite University Hospital) and Paris

(Saint-Anne Hospital). For information, contact the Union nationale des amis et familles de malades psychiques

Unafam, 01-53-06-30-43).



Reason to Hope

For those of you who are not familiar with Reason to Hope, it is an information and coping course for families that is conducted in 8 sessions, either weekly, or as a weekend work-shop. It was developed from the huge body of information that the World Fellowship for Schizophrenia and Allied Disorders had collected over the years on what families need when they find a relative has developed a disease like schizophrenia, bipolar disorder or depression.

The course covers all aspects of these illnesses that may be met or experienced by families or close caregivers. A list of the course content can be found on the WFSAD website which will continue to run until all aspects of the merger with WFMH are complete.

<http://www.world-schizophrenia.org/activities/RtH/Reason%20to%20Hope.html>



Recent Reason to Hope Courses

Tanzania

Joyce Bamwenda of the schizophrenia self-help group reports that the Dar es Salaam Voluntary Association recently delivered a Reason to Hope workshop to families. She sent several photos of which we reproduce one. Well done, Joyce and all of the instructors and families in your group.

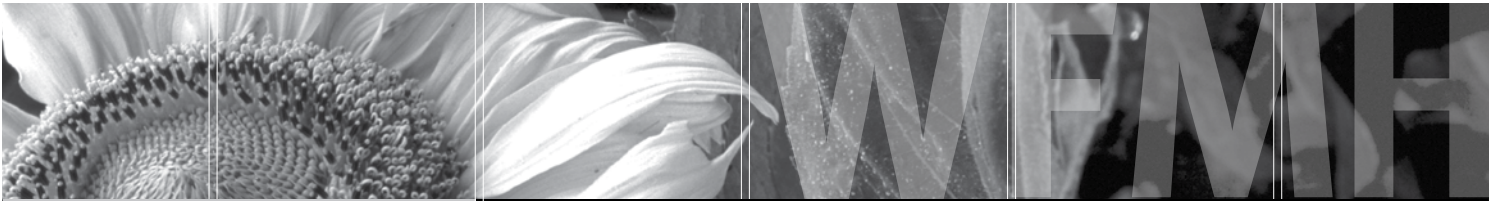


Athens

The World Federation for Mental Health Congress was held this year in Athens from 2-6 September. During the congress Diane Froggatt delivered two half-day sessions designed for families and for potential trainers for the Reason to Hope course. Assisting her was experienced instructor Lilian Kanaiya from the Nairobi, Kenya Schizophrenia Foundation. As those who are familiar with the course know, the optimum number of participants for a successful course is 20. It was a case of first come, first served as there was no pre-registration. The course was oversubscribed by at least 10 and unfortunately these

were turned away, although their particulars were taken for contact later. The second session was designed to explore the contents further while giving tips for the potential instructors in course delivery. Delegates from Australia, South Africa, China, Greece, Israel, Namibia, Malaysia, Norway, Singapore, Scotland and Taiwan took part.

Vassilis and Anna Maria, delegates from Israel whose colleague attended the Reason to Hope Program, standing next to a poster about family inclusion with Diane Froggatt (wearing hat).



Expressions

We do not presume to translate this lovely poem into English. We hope that many of you will get the meaning through the shared vocabulary of the two languages and be able to enjoy the spirit of the work.

Muchas gracias Gabriela.

Metas *By Gabriela*

Cuando la vida te sonría
Cuando todos te admiren
Y te aplaudan
Y sientas que tocas el cielo con tus manos
Ese es el día de tener piedad
Con los carentes de éxito,

Cuando te sientas fuerte y omnipotente
Como un Dios del Olimpo
Y sientas cautivar a todos con una sonrisa
O con una mirada fugaz
Esa es justo la oportunidad de mirar a los demás
Con los ojos del alma y con benevolencia

Cuando sientas que has alcanzado tus metas
Y que eres un triunfador nato
Y te sientas invencible
Esa es la justa ocasión de ayudar
A los que están acongojados y abatidos por el destino.

Después de haber sido capaz de tocar el cielo
Y de bajar al llano
Conservando tu don de gentes,
Tu ecuanimidad y tu sencillez,
Ese será el momento en que te convertirás
En un mejor ser humano.

Gabriela - Julio 2006 - Lima, Peru
En "Subibaja" el boletín de FUBIPA, Buenos Aires.

<http://www.fubipa.org.ar/>



News from Sri Lanka

JudyJeykumar writes from Kalmunai, Sri Lanka about programs at Base Hospital.

At present we have 16-bedded acute cubicles, 8 each of male and female.

Our rehabilitation unit is under construction, but work is not completed because of financial difficulties. In the future we will use the building for the Psychosocial Rehabilitation Program and a Day Care Centre for our patients in the region.

At present needy patients are admitted to the acute cubicle for a minimum of 7 days and a maximum of 14 days. Due to the shortage of beds we send the patients on parole and then discharge from the ward. We follow patients using the nearest of the 13 outreach clinics in our region.

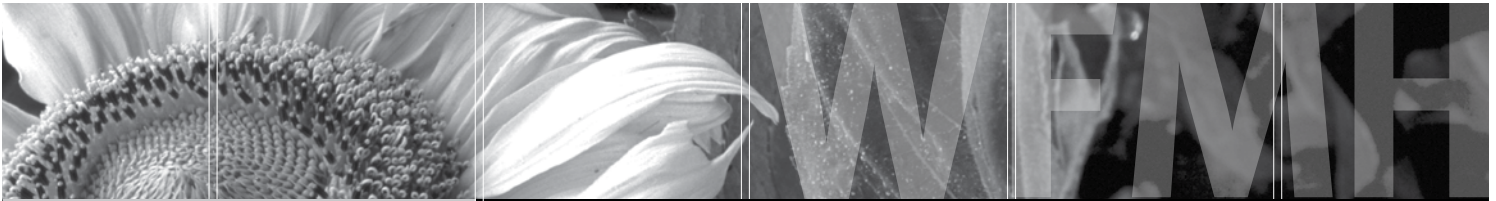
The population of Kalmunai is 300,000. Our hospital only has inpatient facilities. We have a daily routine in the ward: horticulture is the part of their daily routine in the acute cubicle, where patients are admitted with their family members. We do not have any seclusion or prison-like structure and it is very open. They have considerable freedom. They work in the farm environment on the same schedule as they would do in their home (the main livelihood in the region is farming and fishing; families are involved in agriculture as their main income).

In the photo two patients and our nursing officer and our psychiatric social worker are there in the horticulture project. Patients with bipolar disorder use up the energy of their manic states through their horticultural activities.



Our main objective in the horticulture project are

1. Income generation and poverty reduction
2. Enhancing their self esteem
3. Preventing mental disability
4. Occupying time productively
5. Providing an understanding and friendly environment in the ward.
6. Eliminating the stigma around mental health.
7. Involving the family with their member affected by any kind of a mental disorder.
8. Overcoming side effects of medications.



Carers* asked about their priorities

Through Linda Rosie, of the Mental Health Council (MHC) of Australia we have learned of the MHC Carer Engagement Project which was designed to engage with mental health carers throughout Australia and provide a full day workshop.

Carers were asked to highlight the issues which most affected their lives and mental health carers. Coping strategies were discussed and insights offered. 116 workshops that served over 1500 carers were conducted. Aboriginal and other special communities were included. The results have been compiled in a survey entitled **From Adversity to Advocacy** and will be released as this report is going to press. Our information is obtained from a preliminary flyer.

While the survey described below may be the first national survey of carers in Australia, it is very likely that carers in various local or State groups in many parts of the world have taken part in numerous surveys, task forces, planning initiatives and more up to this time, in the hope that the findings will result in the improvement of their mental health systems. It is therefore incredibly disappointing to read the experiences of carers in 2009 – a time when we would have thought improvements would have long been implemented for consumers and that carers would no longer bear the burden of anxiety in finding appropriate treatment and care for their seriously mentally ill loved-ones.

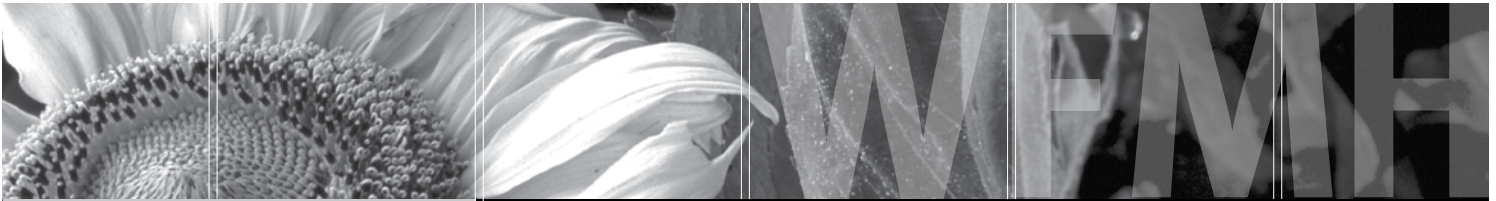
The document states: “Little seems to have changed in the level of access to services when things start to deteriorate, the anguish at being excluded from information to help them care better, and the desperation and desolation at the thought: “What will happen to my son when I am gone?”

Below we reproduce what Australian carers told the survey about their real experience with the system. A second column in the preliminary document entitled “How the issue is currently being addressed” is not reproduced here. You may visit the site listed below to see the whole report.

Issue 1: Listen to and Respect Carers:

The common view among carers is that they are neither listened to nor respected. The rhetoric of including carers as part of the care ‘team’ for the consumer is not borne out in reality. Often this leaves carers trapped, excluded, feeling unable to provide adequate care, but also unable to find the services needed for the person they are caring for.

“Little seems to have changed in the level of access to services when things start to deteriorate, the anguish at being excluded from information to help them care better, and the desperation and desolation at the thought: “What will happen to my son when I am gone?”



Issue 2: Integrated recovery-based care for the consumer:

The intolerable stress faced by carers reflects the inadequacy of the care available to consumers. Of particular note here is the common experience faced by carers of lack of integration between different health services, and between health services and other community services such as housing or employment services, and lack of services such as Personal Helpers and Mentors.

Recovery is very much an individual matter, assessed in the eye of the beholder. The system is not currently able to provide individualised or tailored approaches to care.

Issue 3: More and better trained staff at all levels:

Carers identify inadequate staffing as a key part of current service failure. Access to psychiatry remains extremely limited. Increased access to registered psychology services was not seen as a significant benefit when inadequate workforce numbers impact on availability. Carers report that access to other forms of care, in particular sub acute care, remains a significant issue, particularly in non-metro areas.

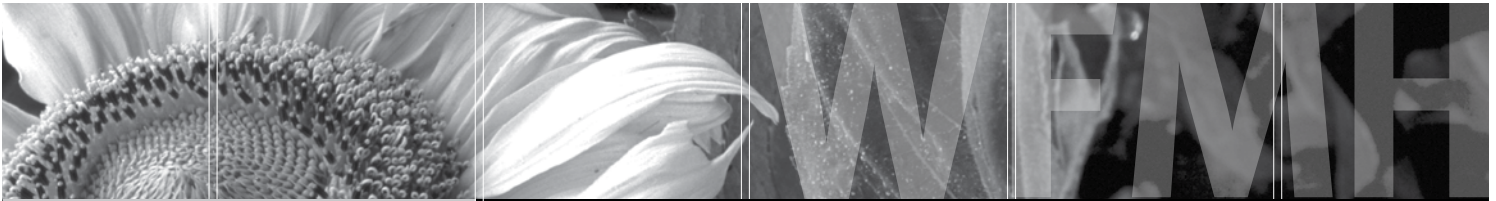
Issue 4: Knowledge and Information for carers:

One of the most debilitating aspects of being a mental health carer is the sense of isolation and helplessness. Knowledge of services such as Commonwealth Carelink is minimal at best. Carelink's understanding of mental health also varies greatly from office to office. Knowledge of peer support options also seems very patchy, with many carers meeting for the first time at the local workshops. Carers reported that the knowledge of how to care for someone with a mental illness was rarely available at first onset illness.

Issue 5: Carer and consumer education for all professional groups and agencies:

Many carers feel ignored or patronised by professional groups and agencies. Most carers feel professionals appear to have no understanding of the role of carers, in particular their integral role in the ongoing care of the consumer. There is a real need for increased carer / consumer informed professional development for mental health and other service providers.

One of the most debilitating aspects of being a mental health carer is the sense of isolation and helplessness.



Carers often use their own resources and pay their own way in order to participate in policy and service development activities.

Issue 6: Support systems, services and processes established for carers:

The need for more carer led support programs for carers was raised in many workshops. The infrastructure to support carers is generally very weak, with some exceptions. Overall, mental health carer organisations are very poorly resourced.

Health services have also generally failed to invest in robust systems to enable engagement with the carer sector. Carers often use their own resources and pay their own way in order to participate in policy and service development activities.

Issue 7: Acute care to be therapeutic and accessible:

The 2007 Survey of Mental Health and Well Being confirmed Australia's inability to lift access to care over the past decade. While the reasons for this are not clear, the impact on carers is very clear. Carers indicate they are commonly faced with providing care to consumers who are acutely unwell, leaving them and the people they care for more vulnerable to the effects of ill health. Carers also considered that acute care (when accessible), was rarely of a therapeutic or recovery oriented nature and often increased the trauma of an acute illness.

Issue 8: Stigma, discrimination and isolation for carers and consumers:

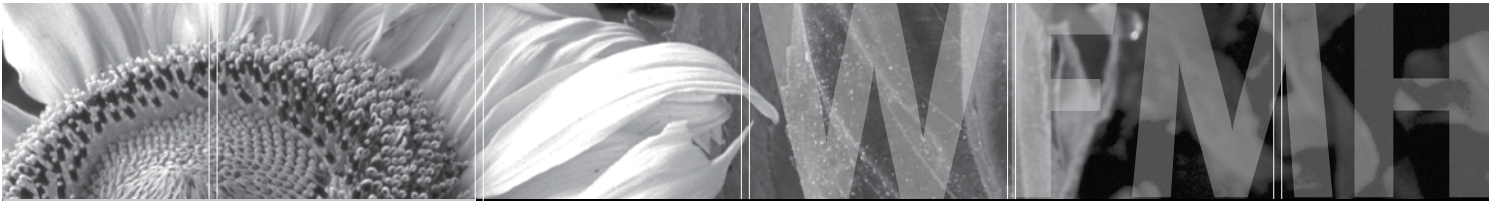
Carers and consumers face daily discrimination and stigma. This manifests itself in the realms of employment, housing, health services, schools, in fact all professional agencies. Sometimes even extended family members can look down on people with a mental illness and their carers. This stigma leads to increased isolation with many carers feeling silence is better than reactions from admitting they care for someone with a mental illness.

Issue 9: Accommodation options for consumers at all levels of care:

Carers report that access to safe, supported housing is a critical problem particularly for consumers with chronic and complex mental health problems. Failure to provide access to housing, or only to unsustainable housing options, leaves consumers very vulnerable to dangers, including worsening health and experiencing violence.

Issue 10: Financial costs to carers:

In the absence of consumer access to regular mental health care, carers often take on complex and time consuming caring roles including meeting



increased costs of transportation or private treatment. The carer role often precludes participation in paid employment leading to significant current and future financial disadvantage for both consumer and carer. Mental Health carers are often refused entitlements from Centrelink which, in any case, only partially defray costs incurred, and rarely allow for the level of support and monitoring involved in caring for someone with a mental illness.

Issue 11: Physical and mental health of carers:

Carers do not feel as though their needs are addressed by anyone. Financially they are not in a strong position leaving them isolated and often facing their own deteriorating health without adequate access to the support they need.

Issue 12: Flexible respite option for carers:

The new respite care program implemented by FaHCSIA has only partially met the needs of mental health carers. Service providers have commonly not understood mental health carers' needs and carers have concerns about respite workers with little or no knowledge of mental illness. As a result, carers do not feel as though respite is a realistic or safe option, and those who try to use the respite services often report problems in finding appropriate options. A possible option suggested by some carers is the collocation of the Personal Helpers and Mentors service for consumers and the respite service for carers within the same organisation (sharing services).

Issue 13: Privacy and confidentiality issues:

Carers' rights to be part of the care team are frequently trammelled as they are excluded on the erroneous grounds of privacy and confidentiality. Carers who were aware of Advance Directives for consumers endorsed their implementation to help navigate the privacy and confidentiality minefield.

Issue 14: Early intervention at each episode of care:

The vast majority of mental health funding remains targeted at acute mental health care. There is only one comprehensive early intervention service for psychosis operating in Australia. Carers are forced to watch consumers wait until their conditions become sufficiently florid to demand the attention of the largely hospital-based acute care system currently in place. This is often despite repeated calls from carers for

Carers' rights to be part of the care team are frequently trammelled as they are excluded on the erroneous grounds of privacy and confidentiality.



help and assistance prior to the issues escalating into more dangerous, unhealthy and long lasting situations.

Issue 15: Employment options for carers:

The poor rates of employment or meaningful occupation for consumers means that many carers are also unable to work or unable to work as many hours as they would like. This leaves many carers vulnerable to the negative effects on physical and mental health associated with financial disadvantage.

For more information go to:

<http://www.mhca.org.au/carers-engagement-project>

We thank Linda for responding to our request for this information.

Linda Rosie, Mental Health Council of Australia

PO Box 174, Deakin West, ACT 2600

Tel (02) 6285 3100; Tel (02) 6285 0810 (direct); Fax (02) 6285 2166

* The word “carer” is used in many countries to denote families or friends in a close caring relationship with a person who is ill. This is the meaning in this article. Other countries use the word “caregiver”. In some places the word “carer” means a professional carer.



Books & Films

Books

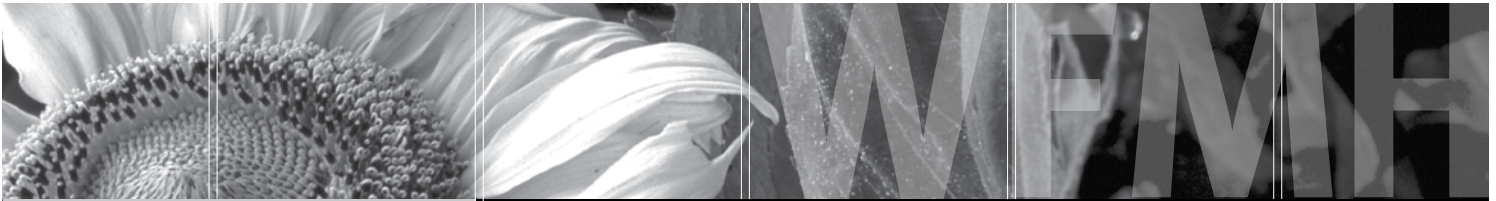
Mind Gone Astray

(259 pages, non-fiction) by Wayne Kallio. Published by iUniverse (www.iuniverse.com), New York, 2009.

While many such stories document the difficulties that families face in getting appropriate treatment for their relative, treatment and care by doctors and hospital staff is not the issue in this book.

Mind Gone Astray is the heart wrenching story of the love of an elderly married couple throughout the first two years of the wife’s suffering with, and treatment for, a psychotic illness. The story, told by the husband, is of his wife Kaija’s increasing belief in internal voices and the increasing demands on him that these set up.





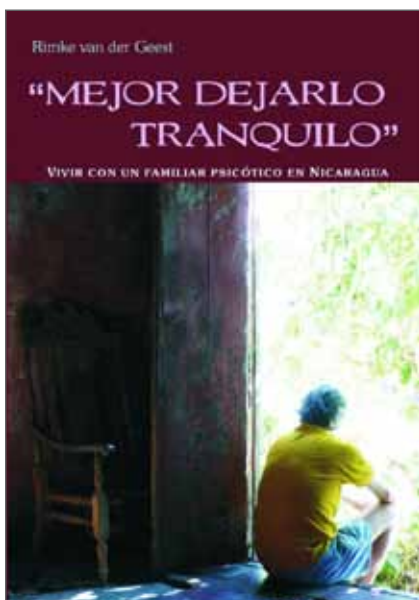
The narrative depicts the undiminishing hope of Charles Koivu (all names were changed to protect privacy), despite the increasingly difficult situation he finds himself in, as his wife fails to respond to medications and even ECT in any sustained way. There is antagonism; there are many tears as they cry together; apologies from Kaija; constantly repeated demands of the voices; increasing numbers of white lies to placate the demands of the voices, and constant efforts by the physicians to find the answer. There is no happy ending here, simply a reluctant acceptance of what the situation becomes. This is an excellent book for those who want to get a real feeling for what the families of those who have psychotic illnesses go through and what their loved ones with illness suffer.

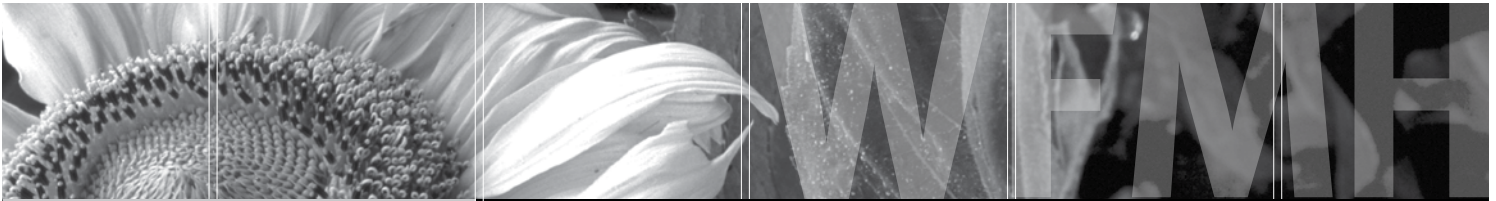
There are several questions left in my mind as to the treatment regimens described in the book. If the author has condensed the time-frame, and there is no reason to believe he has, it is almost unbelievable that within a two-year period Kaija was put on so many different antipsychotic medications. The last doctor we meet tells Charles that it may take up to six months for a medication to work. How is it then that Kaija has had a trial of nearly every antipsychotic that is currently a treatment for psychosis as well as many sessions of ECT within two years?

Many families will find themselves wishing that they had had such caring and interested professionals looking after their relative with psychosis. The sad thing is that despite this care and attention the psychotic illness does not diminish during the period covered by the book.

Mejor dejarlo tranquilo by Rilke van der Geest. Publisher: Uitgeverij AMB, Amsterdam, 2009, Spanish. (Also available online, see below.)

Translation of the blurb (from the Spanish): This book is based on anthropological research and assistance in the Nicaraguan city of Matagalpa. The author visited, over a period of five years, families of which one or more members had a psychotic disorder. The harrowing stories of four of those families are recorded. They are about poverty, violence and the futile quest for healing. The title "Better to leave it alone" refers to the survival strategy that the family applied after years of struggle, in order to manage the future. Besides the families, aid workers also tell their stories. This gives the reader a picture of the assistance available to psychotic patients in Matagalpa and how society thinks about them. Finally, the author describes how she and family members founded a self-help organization to face psychosis and related problems.





This book aims to give insight to students, practitioners and policy makers into the problems of psychosis in Nicaragua. The book is also an argument for psychiatric home care and the involvement of relatives in the treatment of psychotic patients.

You can read the book in Spanish at the “Conta Conmigo” (Count on me) self-help organization site. Click on

<http://www.cuentaconmigo.info/en/publications-en.html>

Promoting Recovery from First Episode Psychosis

A booklet entitled **Promoting Recovery from First Episode Psychosis—A Guide for Families** by Lisa Matens, MSW and Sabrina Baker, MSW, has been published by the Centre for Addiction and Mental Health First Episode Division, in Toronto. In the preface they note that “most young people who develop a first episode of psychosis live with their families or are dependent on their family in some way. We know that you, as a family member, can play a significant role in helping to identify early signs of psychosis, in seeking prompt and appropriate treatment for your relative, and in promoting the recovery process. We recognize that the person who has experienced psychosis needs support; however, family members all need assistance with their own recovery process. The more informed and supported you are, the better the outcome for you and your relative.

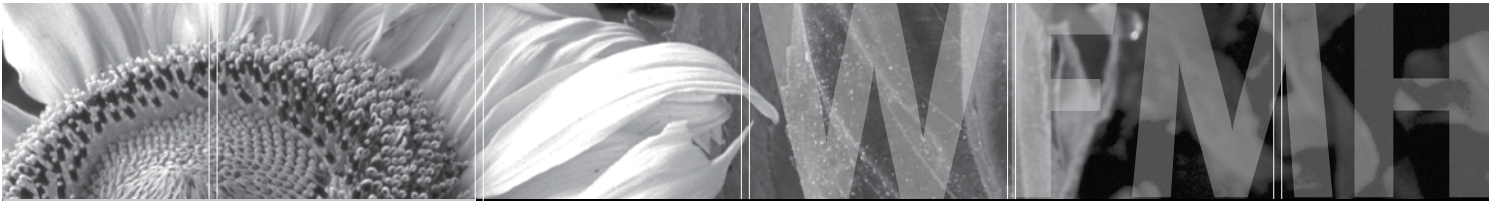
The booklet describes and names the medicines that will be prescribed, their side effects and what to do about them as well as medication compliance (tips are given to assist people taking medication). Many ideas are practical and helpful and there are many direct quotes from families. I would have some concern about describing the phases of psychosis as early, acute and recovery. Families who have a relative with schizophrenia will know that what the general public think of as recovery is not what can be expected with mental illness. Recovery from illnesses like schizophrenia takes a very long time and many, while much improved over several years, will not recover in the general sense of the word (free of disease). This becomes quite apparent later in the book with the testimonials of families. Designed for the families of the program, the booklet could be helpful for families in general.

Family Survival Handbook

A report by Judith Carrington, President, Mental Health Resources, New York.

Historically, families are left without information at the crisis point when it's most needed ---- in the hospital.

We know that you, as a family member, can play a significant role in helping to identify early signs of psychosis, in seeking prompt and appropriate treatment for your relative, and in promoting the recovery process.



In New York, an enterprising family member researched the rights of families of the severely mentally ill into a reader-friendly pamphlet. She convinced the New York State Office of Mental Health (NYSOMH) and grass roots National Association for Mental Illness (NAMI) State to put their logos on when/ Families Join the Mental Health Care Team Everyone Benefits! /This was the beginning of her mission to find a way to get family self-help tools into the hospitals' Emergency Room and inpatient unit as well as to the mental health agencies and programs.

She then made an argument for a **Family Survival Handbook** in which families would be informed about how to be a highly effective partner on the treatment team that the regulations require. In addition it would allow a more level playing field for patients, family and mental health provider's collaboration.

Thanks to NYSOMH's dedication to family participation, they set up a focus group of 40 families to assure plurality of views, sent the documents through their legal and design departments and will be distributing in electronic PDF files, both to the psychiatric hospitals they run and the 2500 agencies they oversee. Both these materials "in the works" can be downloaded in early 2010 on the NYSOMH websites at the New York State Office of Mental Health (www.omh.state.us.gov) and NAMI State (www.naminys.org) websites.

This example of families learning to take over some of the activities of mental health providers, is seen by many in the family movement as increasingly necessary in a period of cutbacks. They also envision that these family authored "rights" and "survival" materials could be a template for other states here and abroad.

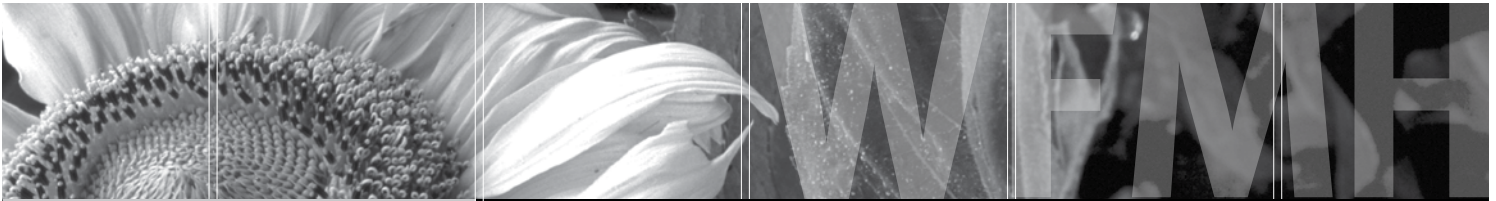
**According to the State Statute, the mental health authorities' regulations and the American Psychiatric Associate's professional standards*

Films/ DVDs

People Say I'm Crazy

– a film by John and Katie Cadigan is the only first-person documentary about living with mental illness (made for HBO in the US), It had its Asian screening at the Taiwan Int'l Ethnographic Film Festival on October 3, 2009. Watch for it to be presented in other festivals.

People Say I'm Crazy (HBO/Cinemax)
www.peoplesayimcrazy.org



Training DVDs: Family Work in Early psychosis

Meriden, the British family service working out of Birmingham and Solihull has produced a set of 5 training DVDs entitled Family Work in Early Psychosis with over 10 hours of viewing. Here is an excerpt from their flyer:

This set of 5 DVDs covers family work consistent with current Department of Health policy and NICE Guidelines:

- The impact of psychosis
- The benefits of evidence-based family work
- Interviews with service users and family members
- The impact of psychosis on siblings
- Demonstration of family work skills with two families
- Discussion with a multi-disciplinary group of expert healthcare professionals discussing implementation of family work
- Cultural factors relevant to family work
- Tried and tested implementation strategies
- The benefits of Carers' Support Groups in early psychosis
- The innovative role of the Carer Consultant in Early Intervention services

The set may be purchased for £200 and is in the PAL video format. There will soon be more information on the Meriden site:

<http://www.meridenfamilyprogramme.com/>

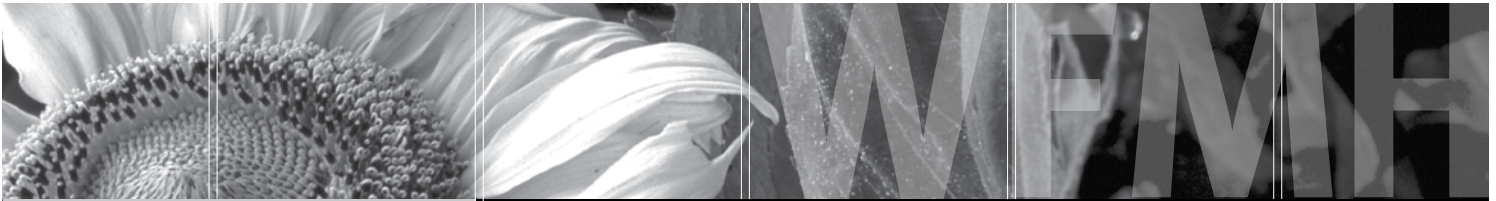


Mentalympians

On World Mental Health Day Mentalympians(TM) announced its inaugural Advisory Group, consisting of twelve advisors based in Australia, Canada, New Zealand, Scotland and the United States of America. Profiles of the advisors are found on www.mentalympians.org.

Mentalympians has been created to develop an online community channel, to be operated through a network of mental health consumer groups. This world-first initiative will establish a 21st century peer support mechanism for raising awareness of recovery; inspiring hope; reducing self-stigma; and connecting individuals to local support groups and services. It is envisaged that Mentalympians will also foster the exchange of ideas and information between groups and individuals to create conditions favourable for social change.

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“The collective knowledge possessed by members on this advisory group is both diverse and exceptional. However, this type of project cannot succeed without the involvement of a large number of people...”

“As President of the World Federation for Mental Health it gives me great pleasure to support Mentalympians as it is a very innovative project to promote both recovery globally and the reduction of discrimination for all people in the world experiencing mental illness,” said advisor Tony Fowke, a member of the Order of Australia and president of the World Federation for Mental Health.

The brainchild of Canberra-based mental health advocate and social worker Keith Mahar, the mental health initiative is itself a testament to recovery, as Mahar’s former Canadian broadcasting career was ended by severe mental illness.

“The collective knowledge possessed by members on this advisory group is both diverse and exceptional. However, this type of project cannot succeed without the involvement of a large number of people,” stated Mahar. “Help is required from members of the public to develop Mentalympians to its potential.”

The mental health community development project is currently recruiting online volunteers. Interested individuals are invited to visit www.mentalympians.org.

For more information email: info@mentalympians.org



Miscellany

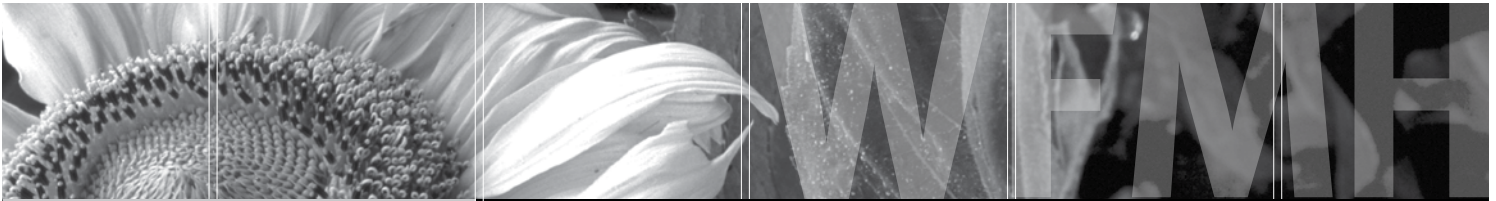
World Mental Health Day 2009 at the Banyan – this from their site:

Clients and care givers from 300 families gathered in a forum for the rights of people affected by mental illness facilitated by The Banyan in Chennai, India. Here their voices were heard by the Social Welfare Minister and the Disability Commissioner, who both pledged their support for the mentally ill. The forum seeks to ensure the implementation of the Disability Allowance for those affected by mental illness, a benefit that will reduce the financial burden of illness on the whole family unit. For more details of the day or for press coverage of the event visit www.thebanyan.org/.

The Forgotten Children

The Forgotten Children is the name of a conference organized recently by EUFAMI, the European Federation of Family Organizations. We hope some of the presentations from this conference will be listed at the EUFAMI site. www.eufami.org

The forum seeks to ensure the implementation of the Disability Allowance for those affected by mental illness, a benefit that will reduce the financial burden of illness on the whole family unit.



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You may also read the current EUFAMI newsletter at: <http://www.eufami.org/images/eufami/main/file/@bulletin%20september%2009.pdf>

BBC News on Mental Illness

On the following site you may watch a video narrated by Peter Marshall on BBC News “Newsnight” about a man holding down a high managerial position who develops depression. During the program Marshall also interviews former **Norwegian prime minister Kjell Magne Bondevik** who suffered mental health problems through his term of office and had to take sick leave. He found that people mainly had a positive response.

He received thousands of letters and many were sympathetic and pleased that he had spoken about his depression openly and told people he had gone for medical help.

“When you are ill you cannot function rationally”, he says. Even small problems were difficult to solve and he could not concentrate, but that was when he was ill and afterwards when he got better he found he could function just as well.

He was re-elected as prime minister. The electorate respected his condition and knew that 1 in 4 people experience mental illness. “Through my sickness I became stronger.”

http://news.bbc.co.uk/player/nol/newsid_7200000/newsid_7201600/7201614.stm?bw=bb&mp=wm&news=1&nol_storyid=7201614&bbcws=1

Nursing Homes not appropriate housing for mentally ill

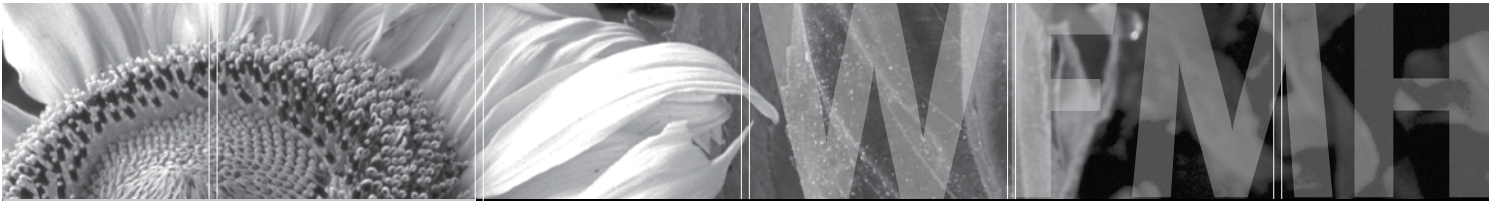
A six-year legal battle in the U.S. to ensure that people with psychiatric illness would not be housed in nursing homes has resulted in the enforcing of the Americans with Disabilities Act. The judge ruled that “New York health officials erred in placing thousands of nonviolent people with mental illness in private nursing homes rather than in independent living situations that provide needed psychiatric care”.

The judge noted that nursing-home residents with mental illness had virtually no privacy, were even more restricted than patients in psychiatric hospitals, and were not allowed to develop skills to become self-sufficient.

An Associated Press report early this year found that people with mental illness are a growing percentage of the nation’s nursing home population: about 9 percent in 2008 compared with 6 percent in 2002.

From a report by Rich Daly in Psychiatric News

Casa Club Bien Estar Celebrates Tenth Year Anniversary



ACAPEF, the consumer and family organization in Córdoba, Argentina, recently announced a fiesta in honour of ten years in operation of their clubhouse Bien Estar. Congratulations! Felicitaciones!

You may visit the ACAPEF website at <http://www.apef.4t.com/>

News from Nicaragua

“Count on Me” is the name of a self help family group in Matagalpa, Nicaragua. “The association is in the process of moving to its ‘own place’, a house big enough for running an office, for small meetings and for starting up a little company “So that we can become independent of funds from Europe”, reports Rimke van der Greet, a researcher from the Netherlands who has been active in developing family support in Nicaragua. Other family/patient groups in Nicaragua, such as ASMEN and ASMEG, have problems to finance their activities, she says. You may visit their website in Dutch, English and Spanish at www.cuentaconmigo.info See also “Books and Films” for a brief report of her book.

Words of Wisdom

To suffer from a mental illness or any illness is not the end of it all.

First: You have to admit you are ill. It is very important for the healing process. Don’t be in denial.

Second: Reach out for the helping hand from your family members, friends or church. They are in the first line. They are very often the first to discover that something is wrong with you.

Third: Rely on the doctors, they are part of the solution not part of the problem. It is very important not to conceal any symptoms from the doctors that might result in the wrong diagnosis. When the doctors know all the symptoms they can give you the appropriate course of treatment.

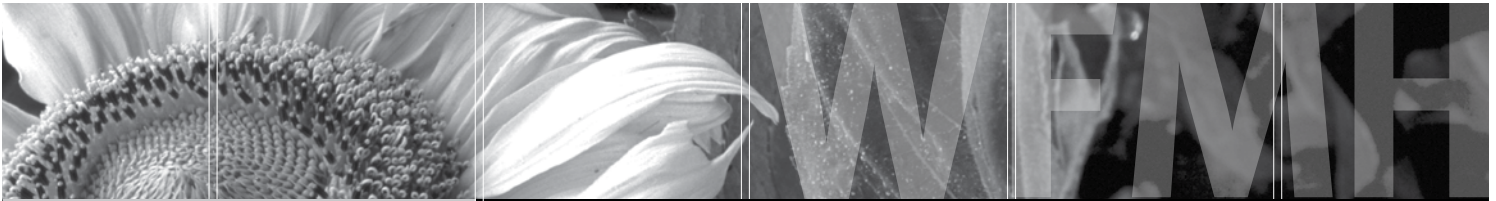
There is a life after the illness. Move forward and make a positive contribution to your society.

From Mr. Stéphane Luako in Lombo, Democratic Republic of Congo.

NAMI Grades U.S. States on Mental Health Care – Nation graded a ‘D’

In 2006, NAMI published the first Grading the States: A Report on America’s Health Care System for Serious Mental Illness. This is NAMI’s second report, building on the baseline of the first. It measures each state’s progress—or lack of progress in many cases—in providing evidence-based, cost-effective mental health care.

“First: You have to admit you are ill. It is very important for the healing process. Don’t be in denial.”



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In their first report, NAMI graded the nation with a D. Five states earned a B and eight states failed the test. In this second report, three years later, NAMI documents marginal progress across the country, but not enough to move the nation from a D grade. Fourteen states increased their overall score over the past three years. For almost half the states (23), their grade remains unchanged since 2006, while 12 states have fallen behind.

NAMI conducted a nationwide Web-based survey, which drew over 13,000 responses from consumers and family members. The results were not used in the grading process, but helped inform the report. Some consumer and family comments from the survey accompany state narratives in Chapter 5. NAMI volunteers also conducted a “Consumer and Family Test Drive” of state mental health agency Web sites and telephone resources to measure the ease (or difficulty) of access to information—which is the first challenge in finding help when it is needed.

In its policy recommendations the report listed increased public funding for mental health care services; improved data collection, outcomes measurement and accountability; integrated mental and physical health care; promotion of recovery and respect, and increased services for people with serious mental illnesses who are most at risk.

For the full report go to <http://www.nami.org/gtsTemplate09.cfm?Section=Overview1&Template=/ContentManagement/ContentDisplay.cfm&ContentID=75091>