

WE ARE NOT ALONE

FAMILY CARE OF PERSONS WITH MENTAL ILLNESS

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“A Family that is educated is a family that is enlightened; a family that is enlightened is a family that is empowered”

—Nirmala Srinivasan

Foreword

The occurrence of mental illness in a loved one is a catastrophic event and often results in enduring consequences for the family. Thus the impact of the illness is experienced not only by the affected member but by the entire family as well. Availability of psychiatric services in cities and larger towns has increased over the years perhaps leading to quicker initiation of treatment. However, the question that confronts most families after symptom control has been achieved is ‘what next?’. Given the paucity of aftercare services, families perforce have to shoulder this additional task as well. This poses an enormous challenge to the families, since it demands considerable time and effort from them in addition to other attributes such as patience, endurance, innovativeness and resourcefulness. It is not surprising therefore that families often feel overwhelmed and helpless in addressing this situation.

Unfortunately many times the attitude of mental health professionals too is not very helpful. Professionals are often quite critical of the way families deal with the patient or adopt a paternalistic approach which fails to recognize and validate the daily experiences – indeed at times, the wisdom – of the family caregivers. This unfortunate scenario can only result in a sense of frustration and dissatisfaction on both sides. A more empathic view would be that caregivers’ behaviors and actions represent the best adaptation that they can make in an extremely difficult situation.

The stark reality however remains that for the foreseeable future families will continue to be the main providers in the care-giving process. In addition families have to also participate in advocacy efforts on behalf of mentally ill persons. While awareness campaigns for many medical conditions have drawn support from public figures, similar gestures are a rarity in the case of mental illnesses. There is hardly any media attention or public discourse on the plight of mentally ill persons. Thus it is eminently clear that mentally ill persons have no ‘visible’ or vocal lobbies or interest groups that are likely to take up their cause. In order to cope with and address these multiple tasks, family caregivers would obviously require and benefit from support provided by mental health professionals. While all families undoubtedly benefit from receiving information about various aspects of the illness, clearly this alone is not sufficient. Families require help at every stage in the illness process, simply because the problems and issues of each stage are different. While many treatment guidelines emphasize the need for some level of

family interventions, it has still not become an integral part of the management and is often left to the choice and inclination of the treating psychiatrist. Families here too have to rely on their own resources and it is in this context that family self help groups have a significant role to play. The daily trials and tribulations of caregivers are perhaps best understood and empathized with only by others in similar circumstances. In this context,

ACMI and AMEND (Self Help Group of family caregivers in Bangalore) have done yeoman service in bringing together Family caregivers. However, it is truly noteworthy that the members have gone beyond just meeting regularly to share their experiences, by crystallizing their collective experiences and insights in the form of a book. It is a simple and practical guide to enable family members to help themselves as well as others who are in the initial phase of struggling to come to terms with the illness. The problem confronting all of us – professionals, caregivers, patients and policy makers – is a huge one and demands a close and empathic collaboration amongst all those involved in the care giving process, based on mutual respect. This guide book is step towards empowering families to become more effective caregivers.

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Introduction and Acknowledgment

Family Care is the backbone for all disabled Indian citizens including those with mental illness (MI) and disorders. The family members are the first to notice changes in the behavior and conduct of their beloved one/s that occurs during the onset phase of the illness. The devastating impact is the same irrespective of social, economic and other differences between families across the world. The moment of diagnosis is the Doooms day that turns cheers into tears; happy families become fatalists and cynics - festivals and friends, family occasions , relatives , holidays and vacations, entertainment down to even the daily routine of walks, going to work, chit chat with

neighbors, vanish from the family calendar. Providing care in the family has become a sub-cultural phenomenon by itself because of the absence of health care facilities and community support.

Starting AMEND Self Help group in Bangalore for the family care givers was an experience that showed sunrise after a prolonged spell of sunset. It provided an opportunity for first person interaction among the affected family members based on the principles of sharing and learning. Struggling with grief, guilt, denial, shame, and stigma are inevitable aspects of the affected family syndrome. Yet a positive and supportive family is an incredible value addition to the quality of life of the patient.

The message therefore was that total faith in medication alone may not help until the family is willing to look into the environmental changes that may be called for. The UN has designated disabled persons as *Specially Abled*. So the chronic care givers become *Special Families*. Caring is an ongoing responsibility and *not burden* as most textbooks mention. Caring is a mission of love born out of faith and hope. This Manual has been written with the sole purpose of making the family care givers understand the nuances of mental illness to face it as a challenge rather than a burden. In 2003, when I received the Ashoka Fellowship, I set up Action For Mental Illness (ACMI) along with my friend and advocate Mrs. Laila Ollapally with the sole purpose of making families as epicenter of advocacy. As part of this mission, ACMI identified a few family members from AMEND who had the potential to become family 'leaders' for a three day workshop to come out with a practical guide for caregivers of the mentally ill. This project was known as KSHEMA. The outcome of this collective effort was later compiled and fine tuned into this present manual "We are not alone", after several rounds of validation from field data that ACMI undertook among urban and rural families through telemedicine. Highlights of this guidebook are FAQs on MI, treatment, rehabilitation, social integration, and the rights and benefits under the Law, coping techniques, communication skills, handling emergencies and inducing drug discipline. This Manual could not have been possible but for AMEND.

I take this opportunity to express my gratitude to Ashoka Innovators for Public, Washington DC for giving me the freedom and support to dabble with innovative ideas by award of the Ashoka Fellowship for social entrepreneurship and innovation.

I am grateful to the enthusiastic support extended by Dr. Ahalya Raghuram, Additional Professor of Clinical Psychology, NIMHANS, Bangalore. The remarkable thing about her involvement was her ability to remain a catalyst giving space for the family leaders of KSHEMA to emerge as change agents. My sincere thanks are also due to Dr. Kalyana Sundaram, MD, Psychiatry, CEO of Richmond Fellowship, Bangalore; he identified the critical issues in family care which helped in the brainstorming sessions with the KSHEMA volunteers; and to Dr. Ali Khwaja, Director, Banjara Academy, Bangalore for facilitating the KSHEMA volunteers training.

I acknowledge the support extended to this Program by the CO- Founder of ACMI, Mrs. Laila Ollapally, Advocate. Special thanks are due to the staff of Nandi Housing Pvt Ltd for the hall arrangements for KSHEMA sessions. Big thanks to our volunteers Mrs. Indira Rangachari, and Mrs. Mary Vinayak, for the extraordinary empathy shown to the care givers of AMEND. The caption "We are not alone" has been coined by Ms. Gayatri Sriram, M.B.A. (USA). Her help in the composition of certain parts of the text is also acknowledged.

Special and sincere thanks to Rotary West, Malleshwaram, Bangalore for its interest to bring out this manual. Today is World Mental health Day and I hope we, the family members make a difference.

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A WORD OF CAUTION

The experience of family care givers of persons with MI across the world is almost alike especially in the emotional aspects. Although, there are lot of similarities in our journey of hope and despair, each patient may need an unique approach. Hence this Manual does not claim to provide thumb rules. It is advisable to consult a mental health professional before you follow any suggestion given here.

About Mental Illness

Mental Illness (MI) is a bio chemical imbalance in the brain that alters the thought process, sensations , feelings, moods and even behavior of any individual. It usually affects adolescents and youth, though not necessarily. Sometimes, the illness can be complicated by drug or alcohol abuse. Major MI are Schizophrenia, Bi-Polar disorder , OCD, Anxiety disorder and Depression. Psychosis or being out of touch with reality need not be always present in all types of MI. Similarly, some individuals have full insight into their illness in spite of psychotic symptoms. Popular belief that nobody is “normal” and so “why make a fuss” delays treatment.. Family members are blamed for “pampering” or “neglecting”. Worse still, the affected individual himself or herself is blamed for laziness and “giving excuses”. Solutions suggested are family holidays, pilgrimage, penance and prayers, changing college or school or job scenario etc. Illiterate folks resort to black magic and other occult practices. Let families understand that while no one is perfectly normal, any changes in the habitual behavior of a person that is odd or strange , preventing him or her from discharging the routine function, calls for a consultation with your family doctor or a counselor. Seek a second opinion if the problem persists. Be sure not to delay any follow up on the advice.

What are the early signs that may indicate the onset of Mental Illness?

Noticeable changes in behavior , moods - suspicious of others; depressed; anxious; withdrawn; tense; irritable or angry. Mood swings, sleep disturbances and changes in appetite, restless , either hyper energetic or hyper exhaustion.

What Causes MI?

The causes are not fully known or nor understood. However, family history, genetic factors, personal trauma, environmental stresses, societal pressures and substance abuse are identified as precipitating factors.

Can MI be treated?

Yes; with medicines and therapy combined with supportive family and / or workplace environment, structured schedule for the consumer or patient etc. Of late, other forms of alternate therapies are also advocated like music, aroma , dance therapy etc. daily routine etc. Other forms of alternate therapies are like Reiki, Pranic healing , music, aroma , dance therapy, homeopathy, ayurveda etc. However, this writer is not familiar with research based publications in these areas. The length of the treatment varies from patient to patient. Lifelong medication may be required in some cases. However, many lead a fairly productive life with ongoing treatment.

The type of MI can undergo changes over a period of time. For example, psychotic symptoms if any may be controlled but anxiety or depression or OCD may step in. Hence family members must keep vigilant about new symptoms or behavior changes and report immediately to the Psychiatrist. Never dismiss any new symptoms or changes in behavior as irrelevant , “being an old case”.

What are the symptoms of MI ?

? There are different types of MI just as there are different kinds of physical illness.

Symptoms differ from each other accordingly.

? Schizophrenia being the most common form of MI is known by its Positive and Negative symptoms. Former characterized by delusions, hallucinations etc; and latter by lethargy, lack of interest and motivation etc.

? Common symptoms of bi-polar or mood disorders are alternating periods of highly elevated moods with periods of deep depression.

? Major depression is rarely recognized as a MI but has severe symptoms like deep sadness, inability to function, loss of all basic urges etc.

? OCD or Obsessive Compulsive disorder relates to repetitive actions following compulsive thoughts that interferes with the individual from carrying out his / her routine functions.

? Anxiety disorder arises out of sudden fears and doubts about known and or hypothetical situations that paralyze the individual into a state of inactivity and dysfunctionality. It may have psychotic overtones.

As lay persons, it is advisable not to find labels for the symptoms that are noticed.

Treatment is given on the basis of the current symptoms though it may cut across different labels of MI. Do not rush to conclusions based on online information available on the net.

Each patient is unique and Psychiatry is for the Person and not for the symptoms.

How do we convince a non co-operating patient to consult a psychiatrist?

This is a common challenge faced many families . The methods adopted are of various types, at times even comical ; not all of them are legally sound under the Mental Health Act 1987. In the long term, it is always rewarding to appeal to the good will of the affected member firmly and consistently using positive negotiation techniques. However it is best to seize the opportunity

when the symptoms are critical to the point of even scaring the patient. In case of those who have discontinued medication, threat of relapse offers ample opportunity to convince the merits of drug discipline to the patient and even some family members.

Some popular methods adopted are mentioned below.

? **Voluntary admission:** Family members openly discuss the issue with the patient firmly and regularly and making him / her understand the benefits of consulting a Psychiatrist. It is a time consuming daily exercise but is most enduring and legally sound. Also, there must be total consensus among family members about the treatment to avoid confusing the patient.

? **Counseling:** Family members can seek the help of a counselor to talk to the patient. If the patient is unwilling the family members can approach the counselor and get tips on how to deal with the situation.

? **Admission by force after sedation** that amounts to getting the patient shifted to the treatment centre without their knowledge. This is a common challenge faced many families. This becomes a case for involuntary admission under the Mental Health Act.

? **Using the help of a friendly policeman especially if there is threat of violence and self harm:** This is rarely followed though we are aware of a few success stories. The Police needs to be sensitized about MI; otherwise, it can turn out to be a danger. Better to get the Police in civilian clothes because after all there is no criminal case involved. Invite him or her for a cup of tea when the patient is at home and ask him to initiate a dialogue with the patient.

? **Proxy / Surreptitious treatment:** This is a common method whereby the families plead with the Psychiatrist to proxy treatment based on their observations of the person believed to be ill. Though many psychiatrists refuse to oblige, it becomes the final hope to avert chronicity. Families resort to it when other methods fail. It is also not desirable in the long run because the patient may not be getting the correct dosage or the correct medicine. A disclosure plan must be worked out with the doctor if at all this method is the only option left.

? **Pre planned admission by laying a trap:** In such cases, one of the family members get admitted in a hospital under the excuse of some serious illness; when the patient visits this member in the hospital, he or she is admitted by force. Apart from being total violation of the patient's rights, this again can generate negative feelings about the treatment permanently.

Families are forced to resort to deviant methods in the absence of Crisis intervention teams or Emergency ambulatory services. When families call for help, they are asked to bring the patient to the hospital without spelling out a safe strategy. Psychiatric Emergency becomes a major nightmare that many families never overcome the trauma of their experience throughout their lives. The reason for not providing First Aid at the doorstep of the patient is pinned down to medico-legal implications under the Mental Health Act for forced admissions and treatment. However this needs to be looked into and amendments made if necessary.

Article 21 of the Indian Constitution guarantees Right to Health and also the famous case of *Paramanand Katara vs the Union of India* (1989, SC Cases 286), wherein the SC has stated that medical emergencies cannot be delayed due to legal process, Emergency facilities have to be provided for psychiatric patients because the nature of the illness is such that majority refuse to meet the doctor. Hence after providing safeguards against violation of rights and frauds, we should have a Mental Health Policy that reaches treatment to disturbed patients.

Demerits of Involuntary Best Practice for Families

Treatment

? Only a short term solution • Be firm but polite and consistent that a visit is in his/ her interest.

? Diagnosis may not be fully • Avoid debating about the correct. consultation or about any particular doctor in the presence of the patient.

? Prescribed medicine may • Keep in touch with the not suit the patient. doctor and prepare him/her also for the proposed visit.

? Dosage may be inadequate. • If possible, let the doctor be sensitized to patient's core fears about the treatment.

? For some mental disorders, • Watch for any gradual medicines are not required; changes indicating patient's instead the Psychiatrist willingness to the visit. prescribes patient therapy.

? It is a violation of patient's • Let the visit be made to rights. appear casual. Family members must remain calm and composed to inspire confidence and trust in the patient.

? Betrayal of trust can occur • Better to select a place at any moment and the that is not too far from consequences are beyond the residence if such a repair. choice is available at all.

? Other relationships in the • Avoid too many delays family can go sour and between visits at least in vitiate the entire atmosphere. the initial stages.

What are side effects of medication?

Side effects vary from medicine to medicine. It is not possible to generalize. But it is better for the family members and the patient to ask the psychiatrist about side effects every time a new drug is prescribed.

What can we anticipate when medicines are changed?

Usually if the patient is doing well on the present medication, new medicines are not introduced. However, in chronic cases that do not stabilize, the doctor may adopt a policy of trial and error with other medicines. But it must be done only after informed consent of the family members and the patient wherever possible. Patients and their families, have a right to seek clarifications on medication changes. They must be sure of the patients' cooperation as well for change of

medication. Taking a joint decision with the patient must be attempted wherever and whenever possible.

What are the implications of either change of medicines or of dosage?

Any change can result in positive or negative patient outcomes depending on many factors both clinical and non clinical factors. However, Psychiatrists must be willing to take the feedback from the patient and the family. Sec 82 of the Mental Health Act, prohibits the use of mental patients as research objects without obtaining their informed consent or that of their guardians.

Will these anti-psychotic drugs dope the patient?

No. In the initial stages, drowsiness is a common side effect which scares family members and some even stop the medication without informing the doctor. Families must report this so that the dosage and timing can be adjusted to reduce drowsiness. Above all, family members need to have lot of understanding and tolerance especially in the first few weeks of introducing medication. If possible, easy to eat food, plenty of fluids and some favorite dishes can be made. Since some medicines have tendency to increase appetite, frequent eating must not be frowned upon. But never stop medication without medical advice because of excess sleeping.

Are these medicines to be taken life long?

There is no general rule. It varies from person to person but it does affect the quality of life to some extent. However, keeping symptoms under control is more important than any other aspect of life. The new generation of atypical anti-psychotics are believed to promote quality of life more than the older drugs. However, these are matters of debate that is best left to the Psychiatrist .

What are the other aids like therapy etc.?

The World Health Organization (WHO) has identified 5 types of treatment methods for mental illness. These are medication therapy, patient therapy, family therapy, social therapy and occupational therapy.

Are these different forms of therapy available in India?

Yes and No. Yes, because as a package it is available in many large mental health facilities under the Govt such as NIMHANS, Ranchi Hospital and State level mental hospitals like IHBAS in Delhi etc.; post graduate institutions like Christian Medical College in Vellore, St.Johns in Bangalore and VIMHANS, RML at Delhi and in other metropolitan cities. However when treatment itself is not available in 500 out of 600 and odd districts in India, it is not practical to expect all other services. The shortage of mental health professionals is a major constraint for using the WHO model.

Family members can take care of many of the needs and rights of the patients so that it compensates for shortage of para mental health services and facilities in your city. Read this Manual carefully and try to follow the Family Based Rehabilitation (FBR) advocated here as far as a viable alternative.

Can MI be cured?

MI is treatable and can be controlled. Many of us believe that medication alone can help in recovery. A combination of medical and social therapy models are required. Most importantly, a positive family attitude **is a big asset**

How can the patient be made to take medicines voluntarily?

This is a common concern for most families. Some simple techniques may be tried like if there are others in the family who take regular medication, then a regular medicine time in the family can be fixed. All medicines can be kept in a common place and the family members make it a habit to take their respective medicines in a manner that is noticeable by the patient. A loving and firm word cautioning the patient about the consequences will be far better

than expressing negative remarks. Preferably, a single member in the family can be identified as a **primary care giver**, to handle all treatment and other aspects. Others must not interfere in this understanding. Any feedback to the primary care giver can be given later. It is better that the psychiatrist is also requested to enforce drug discipline **during each visit.**

Is ECT safe?

Yes. Families have some apprehension about ECTs or popularly known as electric shocks. Though not a permanent or miracle cure, it helps to control symptoms effectively in the short term. It must be administered always under anesthesia **as per the Supreme Court Order.** Consult your Psychiatrist for more information. Side effects are believed to be temporary such as loss of short term or what is known as autobiographical memory.

What is the kind of support one can expect from the Psychiatrist?

It is difficult to record a comprehensive document because the needs vary from each family to the other. Nothing must be hidden from the doctor. Also family members must learn to respect the confidentiality of their ward's symptoms. Other matters that you can expect from the Psychiatrist are as follows.

- ? Information about side effects of medicines
- ? Report on the progress made after every visit if possible.
- ? Reasons for change of medication if any.
- ? Measures to avoid a relapse
- ? Coping with Emergency including
- ? Keeping one dose of Emergency medicine always.
- ? Discharge summary when admitted
- ? Record of treatment if you are shifting to another consultant.
- ? Patient prognosis
- ? Information on counseling if and when required.
- ? Information on family support groups.

How can we make the Psychiatrist give a Report if he or she is not willing to?

This question arises only when you are shifting to another Consultant. Usually, Psychiatrists prefer to talk to each other rather than put it on record. However, to facilitate a dialogue becomes another task by itself. Hence the primary care giver can keep a record of medicines and dosages, changes if any and reasons therein so that briefing the new doctor is simplified. It depends on the circumstances as to whether you would like to keep it confidential. Involving the patient in the preparation of such a log book is one way of making them come to terms with the illness. This has worked in some cases but not always. Yet it is well within your rights to ask for a Report.

Our doctor does not talk much. He writes the prescription fast and sends us off. What do I do?

Unless there is something critical, the doctor may not find the need to spend more time. It is better that the care giver or even the client patient does some homework by jotting down the points that you think needs special attention and showing it to the doctor. Once you communicate your doubts, clarification is bound to be provided.

My doctor tells me not to treat my daughter like a child. But when he talks to her, he says "Mama's baby girl" which offends her.

Talk to the doctor and frankly about your concerns and if it prolongs, change the doctor so that your daughter's treatment is not disrupted. At times, such comments be it by family members or by professionals really hurt the client patients. We must never forget that mental illness does not make a person lose his or her self respect.

My son smokes too much. I am really not able to handle it.

Smoking, drinking or even taking too much coffee and tea reduces the effect medicines. Addiction is also an illness, which needs to be treated separately with different treatment. You are facing two illnesses, and hope your psychiatrist is aware.

Is it good to change the psychiatrist?

Examine your reasons for changing the psychiatrist. Change the doctor only if it is absolutely essential like patient not having a rapport with the doctor; or for other reasons like commuting distance etc. But if the patient is not comfortable with the doctor and wants a change, we are duty bound to respect their wish. Family members are likely to face problem of facilitating communication between the old and the new doctor which normally happens.

What about Yoga and other alternative therapies? Is Yoga good or bad?

Ask your doctor about yoga. They say Meditation is not good for psychiatric patients. But dynamic *ASANAS* are good. Better to consult some experts. NIMHANS , Bangalore is conducting research on Yoga and *Sudharshana Kriya* for persons with MI. But do not stop medicines without the advice of the Psychiatrist.

My brother talks about attempting suicide very often. What shall I do?

Yes, it is a part of the illness and avoids making the patient guilty about it. Anytime your patient talks about it, share with your doctor **immediately**. See if the patient spells out concrete plans or strategies and methods etc. Besides constant vigil, keep reassuring the patient about how much he or she means to the family. Also, emphasize the fact that it is part of the illness and will gradually disappear with therapy and proper medication. Keep giving reassurances. It may be desirable for you to learn from a Counselor about ways and means of reacting to such situations.

What are the warning signs of relapse and what is the solution?

Warning signals are restlessness, anger, agitation, eating problems, sleeping problems, depression, social withdrawal, decreased compliance with medication, anxiety, preoccupation with symptoms, break down in routine, stopping from College or office etc. Once the signals are clear, then the Psychiatrist has to be told. It is better to keep a set of Emergency medication , if advised by the doctor. Prompting an Emergency by admitting the patient on medical advice may also be tried. Family members must reduce their own level of anxiety and panic responses. Though family members are asked to reduce their own level of anxiety and panic reaction, this is not a practical advice at all unless support in a crisis is accessible as in the Western countries.

Handling Emergencies and Coping with Crisis

- ? Reduce environmental stressors like TV / Radio etc for sometime.
- ? Avoid visitors; reduce phone calls.
- ? Reduce routine tasks for the patient
- ? Talk to the patient as to the cause if possible
- ? Promise more support , care and love.
- ? Ensure that the patient is not on empty stomach preferably liquids with sugar to reduce stress.
- ? Avoid family discussions, visitors etc.
- ? Encourage an unscheduled visit to the Doctor
- ? Get a counselor home to talk.
- ? Have a crisis plan ready

- ? Keep emergency phone numbers ready
- ? Administer emergency drugs if prescribed, assuring wellness.

Handling Patients : General Information

1. Learn to express love through respect for and faith in the patient.
2. Show belief in positive family environment.
3. Make special effort to handle communication with the patient.
4. Other communication tips are as follows.

- Verbal interaction or talking must be brief and precise.
- Do not confuse the patients by asking too many questions or giving too many options.
- Avoid emotionally charged statements like “ You have always been a good and nice girl. Can’t understand why this should happen to you” or “The problem is that you are too good or too simple.”
- Positive comments on performance are always welcome.
- Avoid comments on appearance unless patient welcomes it.
- Forget not to compliment even for small tasks achieved like taking a bath.
- Requests and suggestions are better than commands. For example, say “Would you like to take bath before lunch ?” instead of “” You must take bath before lunch”.
- Speak the language of love and respect for the patient in every word that you utter. One way of doing this is to imagine a situation where you would have interacted with the patient had he/ she not been a patient.
- Avoid discussing issues related to the patient in their presence with neighbors and visitors. As far as possible , respect their right to privacy.
- Unless suggested by the doctor, avoid discussion about symptoms with the patient. But sincerely listen to the patient even if he or she is talking symptomatically.

A Caregiver Writes.....

I used to wonder why my daughter gets very angry with me and my wife. Our very presence makes her either irritable or silent. When I was sharing this in a Support group, another parent told me that there are two reasons for this. One is because MI persons are too scared to take out their frustrations against outsiders. Secondly, as a family, there is shared history which they detest because of their unfortunate condition. Medication alone will not set right the problem. Myself and my wife visit a counselor regularly to change our behavior and communication style. It has helped a lot to bring in some peace.

Rehabilitation- General Information

“Many consumers (or patients), mostly those who have seen improvement in their condition, have come forward to say that there is more to their lives than disease and symptoms of disease and they want their carers to have a holistic approach to treating them. They have stressed that even with some symptoms they can function if given the opportunity to develop or regain skills, to develop support networks and regain the self-respect that many of them have lost owing to periods of ill health.”

Diane Froggatt “ Getting your Life Back” Cover Story from World Schizophrenia Newsletter 2004- 05.

Diane is a carer herself.

Rehabilitation is the intervention adopted as part of the treatment to make the patient (also referred here as consumer) perform tasks on a routine basis when there is some relief or remission from symptoms. The routine tasks are structured into a schedule that may extend from the simplest task of personal hygiene and self care to more challenging tasks like getting back to college or work etc. Currently, the term “reintegration” is in usage more than “rehabilitation”. Usually it is at this stage the mental health professionals like the Counselor and Psychiatric Social worker who add value to the treatment process by therapy and structuring a schedule. By and large, most Psychiatrists give an indication to the patient and the family as well about roadmaps to rehabilitation.. Very few psychiatrists have the complete team of mental health experts working with them to provide assistance in therapy and rehabilitation. Then it becomes the primary responsibility of the family to take charge. However, there is no guarantee of a linear progression from treatment (or hospital phase) to rehab to recovery. MI is a roller coaster ride and let us be prepared for it as a challenge rather than a burden. .

In metropolitan cities like Delhi, Bangalore and Chennai etc, a variety of rehabilitation facilities can be outsourced. These are Day care centers, Halfway homes, vocational skills centre, sheltered workshops, therapeutic groups , self help support groups etc. Long-term homes are for those who are unable to be looked after in the family for many reasons. There are lifelong care centers for patients who cannot take care of themselves.

In the long run, to integrate the patient emotionally, socially and physically with the day to day happenings in the family is a better proposition than seeking residential facilities outside. Unless, the Psychiatrist advises separation of the patient from the family, or unless it is absolutely impossible to keep the patient at home , HOME / FAMILY is the best rehabilitation ground. FBR or Family Based Rehabilitation program is a challenge for the care givers ; but is perhaps the most efficient model for many who cannot afford private commercial services in the community.

FAQs on Rehabilitation and related issues

What are the benefits of rehabilitation? Many of us are not aware of the fact that MI has dual aspect to it- disabilities besides symptoms; most of the patients are also affected by some form of disability or the other. These are disguised and not visible as in the case of the visually impaired or orthopedic handicapped persons.

Rehabilitation is expected to help the patients handle if not overcome their disability and learn how to cope with the routine tasks with symptoms alongside.

What are the disabilities in MI?

Disabilities in MI can be grouped into **cognitive** (like attention deficit, memory lapse), **emotional** (like being unable to relate naturally in interactions) and **social** (interpersonal and other social skills) . Not all disabilities are present in all the individuals at the same time. Regular counseling helps to handle and cope with some of these disabilities.

Is rehabilitation possible when patient is still on medication?

It is very important for the patient to have a schedule at home so that he / she can get back to functional levels very soon. Keeping the patient occupied and busy is an important responsibility but it is not possible to do this unless proper medication is given.

How does therapy help the patient and the family?

MI is a devastating experience for the families; and of course, nightmare to the patients. Under these circumstances, therapy helps the family- patient dynamics in a manner that it reduces emotional burden on both so as to carry out the rehab program with minimal disturbance in the routine.

How do I select a rehabilitation centre?

The consulting Psychiatrist usually provides information on this. All institutions for mentally ill must be licensed by the govt. under the Mental Health Act, 1987; Board of Visitors must visit every month and a report is to be prepared on the visit.

The patient is sleeps too much and is unable to follow the routine. What do I do?

Consult the Psychiatrist to alter the timing and dosage of medicine if required. Lethargy and apparent lack of interests pose major hurdles in motivating the consumers. Be patient and does not express too much expectation. Things are likely to change gradually.

Principles of FBR

1. Patient's co-operation can be sought by requesting the Psychiatrist to initiate the rehabilitation process or help in identifying a Psychiatric Social Worker for a guide. This helps in promoting an understanding between patients and families.
2. Start with indoor chores like making a cup of tea or coffee, simple breakfast or helping in other chores like filling up water , watering plants, gardening etc. followed by exercises or going for walk; finally outside assignments can be tried. Outside jobs like bank, post office or other shopping like vegetables etc. can be done with the support of family members to begin with.
3. The family has to constantly remember that the patient has some deficits or disabilities such that it may not be immediately possible to get back to the same level of functionality as before. Lowering down family expectation is very important. Similarly, at times, the expectations of the mental health professionals may not be practical for families to handle.
4. Many educated families have some fixed notion about the kind of jobs or tasks their wards must perform. For example, if the patient is a drop out from College, and is asked to do book binding, families do it meaningless. However, remember these are stepping stones to get a routine and not pick up any skills.
5. Unless the consumer is comfortable, do not force interaction with all visitors and relatives. They are sensitive to uncalled for comments that hurts everyone. Either make it a non issue by ignoring it or share it with the relevant people that she is under treatment and that you need their support. However, you must use your judgment as to with whom, how and how much you are going to share.

6. There will be ups and downs in the daily schedule implemented by the patient. Since the illness can take up a heavy toll on their skill sets, it is not possible to expect the same level of performance as before.

7. Patient's capacity to engage in activities and interaction is like a barometer for the Psychiatrist to titrate medication. So family's observation is a vital input in the course of rehabilitation.

Shantha is the 22 year old daughter of Lakshamma . She accompanies her mother to work in the garden every day. Lakshamma gives her work as if she is not ill at all. She does not show any anxiety either about the illness or about rehab. When Shantha does something , she remembers to praise her; when she sleeps under a tree, she does not get upset with her. She respects her daughter ; never complains about her to anyone and so others also respect her.

Other FAQs on Rehabilitation

What do I need to know about rehab centres outside FBR?

These are known as community based rehab centres or CBR centres. If rehabilitation is not happening in the family but in an outside service, then the family members have to find about security arrangements in the place , medication administration, visits to Psychiatrist, activity schedule , diet and exercise , feedback on patient's progress , family therapy, patient therapy etc.

Under the Mental Health Act 1987 , licensing is mandatory for all mental health facilities.

Under the Persons with Disabilities Act 1995, all facilities for disabled persons must be certified.

How can I find a 'suitable job' for my sister?

It is always better to identify the a list of suitable jobs with the help of the Psychiatrist and Psychiatric Social worker. Here are some tips.

- ? Opt for voluntary work in the beginning.
- ? Start with part time and increase gradually.
- ? Accept some slackness in the household chores
- ? Ensure reporting to a single boss.
- ? Share with the employer and the immediate boss about irregular attendance , frequent breaks nature of work, safety etc.
- ? Furnish a letter from the doctor if required provided the consumer is comfortable with the disclosure.
- ? Avoid initiating discussion about the office, colleagues etc. unless the ward has something to share.
- ? As far as possible, let the patient handle issues at work and avoid making confidential calls to the boss or colleagues unless the ward is disturbed or the verge of relapse.

Persons with Disabilities Act 1995 provides job reservations for persons with physical disabilities but not for MI and MR. Social stigma and myths about MI, the deficits of the illness are other challenges that make equal employment opportunities almost impossible. A recent development is the signing of the UN Convention for Rights of Persons with Disabilities 2006 by India gives equal job opportunities to persons with MI on par with others.

My daughter's colleagues keep asking her why she is not married?

One patient faces this question with a sense of humor. He tells them that he is waiting for them to find a bride; and he adds that he is sorry to see their disappointment. But it is difficult for all patients to do this. It depends on the comfort of your daughter about sharing. Otherwise, some noble lies can always be invented.

Is marriage a solution to MI?

No. Nor is it a taboo. It depends on the patient's ability and willingness to undertake the responsibilities in a marriage. It is better to seek medical opinion before finalizing anything. The policy of disclosure and not hiding anything from the prospective alliance is to be strictly followed. Unfortunately, failures are more common.

AMEND provided the forum for an arranged marriage between two consumers . The marriage is now going steady for the seventh year. Another consumer of AMEND married with the help of his Church and is a proud father today. A third consumer is happily married and is about to become a mother. We have had our share of failures too. As in the case of normal marriages, it is advisable for family members to stay out of the situation and allow the consumers to sort out issues. The best support to be extended by families is to introduce a Counselor to their consumers.

Who will look after my child / spouse after me?

This question has no definite answer. It is matter of deep concern to families giving them sleepless nights. Many options suggested below are more of academic relevance for families. Hiring lifelong care is neither possible nor affordable. Just see if you can identify someone – **a special someone** who will keep a watch if in case the patient is orphaned. Other options given below can also be explored depending on specific situation in each family.

- ? Supportive relationships from peers / cousins or friends
- ? Self care and management skills to be imparted if possible
- ? Prepare the sibling with adequate training
- ? Set up a private Trust
- ? Ask the doctor about prospects of marriage.
- ? Identify long term homes.
- ? Start a self help group and make it a project in the group for which Govt. of India, Ministry of Social Justice and Empowerment provides grants.
- ? Fight for the rights of the destitute locally with your State Government.

Carer and consumer support groups must ask the Government to provide simple and safe options that are affordable to the common Indian. The demand for long term homes are shunned by many mental health professionals and officials as reviving the asylum model of care. However, when confronted with the question of "Who after us?" none of them are able to offer a satisfactory solution because we are aware of the only available alternative viz., Street care.

Tips for Family carers

by

Dr. Ahalya Raghuram

- ? It is important for family members to get back to a normal daily routine as soon as possible after the onset of the illness/relapse, and to adhere to it as much as possible.
- ? Family members must take some time off every day to refresh themselves from care giving tasks. This time must be used to engage in relaxing, recreational activities and not in other tasks or chores.
- ? Family members should avoid feeling guilty/anxious about taking time for themselves. It is beneficial for themselves and also for patients to have some 'space' and time alone, away from family members.
- ? Families need to learn to 'selectively ignore' by not paying attention to the less important aspects of the patient's behavior. This will decrease stress on themselves and the patients too.
- ? Family members may need to express their feelings (anger, frustration, apprehension or disappointment) occasionally. It is important to find a 'safe environment'; to do so, in the absence of the patient.
- ? Families should maintain their links with their relatives or friends. How they interact with the patient is an important lesson for others outside the family to also learn from and is a form of education for them.
- ? It is helpful for family members to be as open about the illness as they feel comfortable with. This avoids the further stress of creating a false picture about the patient and having to sustain it.
- ? It is helpful to join a self help group of family caregivers to share experiences and to learn from others' experiences.

Rights of family caregivers

There is no Law that recognizes or spells out the rights of family care givers. The courage and determination, love and dedication of family members goes unnoticed. At times, family members are accused of "dumping" or abandoning, or even exploiting the rights of their wards by forcing them into treatment and rehabilitation. The lack of support systems for family care has not drawn sufficient official and legal attention. There is no help to shift a symptomatic patient to the hospital; nor are affordable mental health services available within reach of the affected families. The role of Indian families handling the challenge especially in context of poverty and MI needs to be taken seriously by the policy makers. Providing support and care for carers is ignored in most policies and programs because families are not *visible* !

The UK Mental Health Act spells out the rights of family guardians explicitly in many sections. The Mental Health Act in India permits relatives of persons with MI to apply for admission of involuntary patients , discharge, legal guardianship etc. Even if family members are natural guardians, they have no right to legal guardianship under the legislation. Other unwritten rights are as follows.

- ? The right to information on the illness to the extent it is in the interest of the consumer.

- ? The right to the fullest extent possible participate in decisions regarding treatment, discharge, rehabilitation and other needs either as supportive or as substituted decision maker.
- ? The right to discuss the case with mental health professionals.
- ? The right to seek information on prognosis for purposes of future plans.
- ? The right to obtain official documents either on behalf of or for the consumer. This includes discharge summaries, treatment report if change of therapist is involved, disability certificate etc.
- ? The right to protect the rights of their loved ones.
- ? The right to apply for disability certificate.

As far as rights of family members are concerned, there are more questions than answers as stated below. The UN convention for Rights of Persons with Disabilities 2006 makes special mention for Supportive guardianship as a legal provision to be included in law of the land.

Rights of Family Carers ?

- Do family carers have any rights at all?

- Do families have a right in legal process such as involuntary treatment and admission etc?

- Do families have the right to file FIRs on missing patients?

- Do families have a right to be legal guardians?
- Do families have a right to appoint legal guardians for their carers?
- Should family carers be involved in Inspection and licensing ?
- Should families be involved in policy formulation?
- Should Law spell out the legal status of carers?

Information for rights and benefits of Indian citizens with MI

1. The Mental Health Act 1987 and the Persons with Disabilities and Equal Opportunities Act 1995(PWD Act) are two major legislations in India relating to the needs and some rights of persons with MI.
2. MI has been recognized as a **DISABILITY** under PWD Act. This falls under the purview of Ministry of Social Justice and Empowerment, GOI Shastry Bhavan, New Delhi -110011. Other contact details are <http://social.justice.nic.in/> . Contact Jt.Secretary, iisd@sb.nic.in/ tel.no. 01-23381643
3. Under the PWD Act, any injustice or cases of discrimination against MI can be reported to the Commissioner for Disabilities of your State. If the information is not available, contact Ministry of Social Justice and Empowerment as per details given above.
4. Under the PWD Act, persons with Mental Illness are entitled to Disability Certificate and the Identity Card . The certification is a mandate under the PWD Act. It will be issued after administering a test called IDEAS. Contact the Disability Commissioner of your State for further information. Some States have only certificates and no cards.
5. The Disability certificate helps in obtaining all benefits on par with other disabled persons under the PWD Act. Some of the benefits are bus nad railway concessions, self employment loans, Income tax rebates, maintenance allowance for those below the poverty line.

6. Income Tax benefits can be claimed under Sec.80DD and under 80U of The Finance Act, 2003. Consult any Chartered Accountant for more details.
7. Under the Indian Trust Act, private TRUST can be formed for the patient without mentioning the illness in the TRUST deed. Interested families can contact any lawyer to set up the Trust. It is safest to set up a TRUST because under the present situation in view of the guardianship laws mentioned in the Mental Health Act 1987, the property of the ill person can be acquired by the Court if the person is not able to handle it.
8. State Bank of India's Estates and Securities Cell offers to be trustees or a co-trustees. Contact SBI in your city for more details.
9. LIC has a special disability insurance policy. If by chance, the policy is denied to the MI category, report the same to the Commissioner For Disabilities. (*see item.no.3 above*).
10. The National Handicapped Finance Development Corporation (NHFDC), at Red Cross Bhana, Sector 12, Faridabad, 121007. Tel. no. 0129- 2280335 / 22264841 / 2280214. Fax- 22284371 is distributing loans to all disabled persons for education and self-employment activities. Each State has a nodal agency for distribution of loans.
11. The Ministry of Social Justice and Empowerment provides grants for running Day Care and Half way homes. Those interested may contact the Ministry *vide* item no.2 above

Family members are usually trapped in a medical mind set that prevents them from seeing anything positive beyond the illness. Participating in advocacy activities by joining support groups helps them to handle their issues better. However, many join such groups to *set right* their wards rather than use it as a learning forum for themselves or for the Cause. In fact, activism helps in not only understanding one's own issues better but also helping ones resource base as well. India needs a Voice from the consumer and caregiver lobby.

Some Services and Facilities in India (The list is not exhaustive)

1. Assam, Guwahati, ASHADEEP, societyashadeep@yahoo.com ; 0361 2666794
2. Ahmedabad – SAATHI, kcbanker@hotmail.com ;
tel. no. 26813500
3. Bangalore- AMEND- amendindia@hotmail.com
4. Bangalore – ACMI, acmiindia@yahoo.co.in .
5. Bangalore- Dr.Ali Khwaja, Director, Helping Hands ;
080-2353578 . This is a contact point for all other facilities in Bangalore and India.
6. Chandigarh : ajaymehndi@rediffmail.com;
7. Chennai - AASHA , kromatics@vsnl.com, 044- 25370735 / 9840088031
8. Chennai- SCARF , scarf@vsnl.com; 044-26151073; 26153971
9. Chennai- THE BANYAN;banyan@vsnl.com ;
044- 26530504 /265310
10. Delhi- SANJEEVNI :011- 26862222/ 26864488

11. Delhi- RFS,Noida- 0120- 3223331
12. Delhi- ACMI – acmiindia@yahoo.co.in
13. Goa, ADHAAR : ngawas@sify.com ;0832-2201210
14. Goa COOJ : petercastelino@hotmail.com; 0832- 2253450 / 2265555
15. Hyderabad - NAMI INDIA –consult@msjoshi.com; 23227649 /232244167
16. Jharkand, Ranchi ,sunrise_sushilks@yahoo.com ;
0326- 2253348
17. Lucknow- RFS- 0522-2789200 / 220
18. Kolkatta , TurningPoint ,ishitasanyal@hotmail.com ;
033- 24392316
19. Kolkatta- Paripurnata Halfway Home ,ppurnata@vsnl.net) ; 033-23504073
20. Kolkatta – ANJALI- anjali_i@vsnl.com;033- 22403711
21. Mumbai, IPH, iph@healthmind.org
22. Mumbai- Tata Institute of Social Sciences – 022- 25563289 to 92
23. Mumbai, MAITRI , hshetty@vsnl.com;022- 26841658 / 26840720
24. Mumbai- NAMI INDIA – nami@namiindia.com :
022- 26288620
25. Pune , SAA , saa2003@vsnl.net; 020-24483650
26. Palghat (Kerala) , Margadeepthi , 04923-2229000)

Facilities at Bangalore

- 1.Richmond Fellowship society (India).
Asha, Jyothi, Chethana. Ph - 26645583, 2244673
2. Medico pastoral association. Ph - 25477375
3. Cadabams group of psychosocial rehabilitation center. Ph -28432866/988
4. Family Fellowship Society for Psychosocial Rehabilitation. Ph - 9886013334
5. Raju’s Rehabilitation Foundation. Ph -25531145/25521773
- 6.Mind Medical Center. Ph: 98440 13253 / 25511276
7. Athma Shakti Vidyalaya Society. Ph - 26581564
8. Andrews Rehabilitation Trust. Ph – 25420608
9. Friends of NIMHANS Trust. Ph: 51128494
10. Navachetana Rehabilitation Center. Ph: 26786409
11. Spandana Rehab., Research and Training Centre – Ph.23595652 / 23493157

12. Integrated Multipurpose Recreation & Hobby Center.
Ph: 26574258