Manual 3

Caregiver training manual

(Savita Apte)

Training Manual for Care-Givers of people with lived experience of Schizophrenia.

This manual appreciates the journeys of persons with schizophrenia and their caregivers. There is hope for all of us as we traverse this path from illness to wellness. IPH also shares the *Dwij Puraskaar* experience to help us all understand the power of defeating stigma and empowering families.

Broad contents:

- About IPH
- IPH work on schizophrenia.
- Why the need for this manual?
- Training Modules.

A] Know more about schizophrenia and what your loved one is experiencing

- Why Caregivers?
- Understanding schizophrenia and symptoms.
- Treatment choices available in India.
- Side effects.
- Functioning of the person suffering from schizophrenia.
- Insight developed by the caregivers and the shubharthi.
- Causes of Schizophrenia.

B] Handling day-to-day challenges while dealing with the Shubharthis.

- Day to day challenges experienced by the caregivers.
- Understanding the symptoms. How often, How strong, How long they last.
- Understanding what Caregivers CAN do, and what needs to be accepted since it cannot change.
- Understanding my limitation as a ' caregiver '.

C] Coping with the emotional challenges faced by the Shubhankars.

- Understanding the concept of empathy.
- Rational Emotive Behavior Therapy model to understand the extreme emotional disturbance of the Caregivers. This session throws light on understanding the thoughts and beliefs that cause extreme emotional disturbance.
- Identifying core unhealthy beliefs troubling the caregivers.
- Replacing unhealthy beliefs with healthy rational beliefs.
- Healthy acceptance.

D] Communication.

E] Socialization& related issues.

F] Forming caregivers support group.

G] Forming a rehabilitation set-up for non-functioning or partially functioning Shubharthis (people with lived experience of schizophrenia).

Manual for Training the Caregivers of Persons with Schizophrenia.

About IPH

- Institute for Psychological Health (IPH) is a Non-Government – Organization working in the field of community mental health since 1990. Our website www.healthymind.org gives in detail the expanse of our work in community mental health. We are situated in Thane on the outskirts of Mumbai, Maharashtra state, India. We also have additional center in Pune (2018) and Nasik (2020).

- IPH (Thane) today has more than 75 mental health professionals working together with a common cause of destigmatizing mental illness. Our team consists of trained psychiatrists, clinical psychologists, counseling psychologist, educational psychologist, remedial therapists, social workers, occupational therapists and nearly 250 community volunteers working on different projects related to mental health.

- IPH proudly started its Pune center in March 2018, which is blooming with different activities including psychiatric consultation, counseling, training, support groups and much more.

- IPH Mindlab Nasik started its functioning in October 2020.

- Way back in 1990 IPH Thane started its services by giving one to one psychiatric consultation and counseling to the needy. There was a lot of stigma about taking help from a mental health professional. Gradually people experiencing some amount of emotional or psychological issues were increasing.

- IPH conceptualized the model of 3 D i.e. Distress, Disorder & Development while understanding the response of the community to the services provided by IPH.

- Team IPH realized that people initially came to IPH when there were problems like addiction, depression, anxiety, schizophrenia, academic or occupational failures etc. These were the people who had some type of psychiatric illness or disorder.

- Family members who got them to IPH or came with them had difficulty understanding the gravity of situation and were at dis-ease level.

- Changing social scenarios possessed different challenges to people which caused distress to them.

- IPH started understanding the needs of these people and developed a range of services to address it.

- This helped in achieving the fourth D- Destigmatization.

IPH work with schizophrenia:-

- After establishing the center in March 1990, IPH regularly started getting families who had people suffering with schizophrenia - Founder trustee of IPH Dr. Shubha Thatte already had her Ph.D. on schizophrenia. Under her guidance another trustee of IPH Dr. Anuradha Sovani was completing her Ph.D. on positive and negative symptoms of schizophrenia.

- In the decade of 1990 IPH organized two important conferences. One for the family members of schizophrenia and other one describing the rights of people suffering from schizophrenia in 1996.

- During this decade IPH team was observing that there is gradual increase in people taking help for different psychiatric ailments. Schizophrenia was one of the most important disorder of it. Along with the person suffering, the family members were also stressed to a great extent. They experienced emotional pain, burden, burnout & stigma. They felt lonely and isolated from society because of their challenges. Understanding their needs and addressing their issues was extremely important.

- Ms. Savita Apte, Clinical Psychologist at IPH decided to do her Ph.D. under guidance of Dr. Anuradha Sovani. Focus of her Ph.D. was understanding the needs of caregivers of schizophrenia and developing training modules for reducing the stigma, burden and burnout experienced by the caregivers.

In its journey of working with people suffering from schizophrenia, two important terms were coined. We started addressing people suffering from schizophrenia as '***Shubharthi***' and their family members, their caregivers as '***Shubhankar***'. 'Shubharthi' is the one who is on the path of recovery, the one who is aiming for wellbeing, wellness. 'Shubhankar' is the one who is wishing good, helping the person to achieve wellbeing. This was an attempt to destigmatize the psychiatric label. In this manual Shubharthi and Shubhankar words are used for person suffering from schizophrenia and their caregivers respectively.

Why the need for this manual?

- As a result of Dr. Savita's doctoral work, three important things happened in the history of IPH.

  - A caregiver support group was started in 2004.
  - Tridal - a rehabilitation workshop was established by the professionals & caregivers for non-functioning schizophrenia patients.
  - A training module for caregivers of schizophrenia was developed and regular training for the caregivers started since 2005.

Training Modules.

This manual is an attempt to document these training modules. These modules are carried out over last 15 years. Many caregivers have benefitted to a great extent with this training. These modules can be replicated anywhere in India or in the Indian sub-continent. After taking into consideration certain cultural aspects these modules can be tried in the other countries also by the professionals and trained volunteers or caregivers.

There can be different ways of starting this training. This training is spread over two days and has 4 sessions of three hours each. Other option can be of dividing the modules into 4 sessions of 3 hours each over 4 evenings or two weekends. It's better to have two facilitators at a time.

Making the Modules interactive works well. We at IPH mostly start our training with the Module C - Coping with the challenges faced by the shubhankars. Followed by Module B - Handling day-to-day challenges while dealing with the shubharthis. This is covered on 1st day of training. On second day of the training, we start with Module A on Psycho-education and Destigmatization session, followed by modules on communication, socialization, forming support groups and question and answer sessions. Addressing the emotions of the caregivers at the start of the trainings helps in their acceptance of the other information. If the facilitators are comfortable starting with the psycho-education and destigmatization module, they can try that too. It is advisable not to start with the Module B - Handling day-to-day challenges. Facilitators can also convert this information into power-point presentation for the training.

Initially we were doing this in reverse order, but found through experience that starting with psychoeducation is not very useful, and we form a better connect with the learners by starting with Module C.

Section-I A] Psychoeducation& Destigmatization. Let us know more about schizophrenia. We can overcome problems and difficulties only if we know them well first.

Introduction:

- The training starts by introducing the facilitators.
- Second introduction will be of all the participants who are attending the training. While introducing themselves they are expected to tell.

    - Their name.
    - Who is the Shubharthi (person with experience of schizophrenia) in the family (relationship)?
    - Age of the Shubharthi.
    - What is he/she doing?
    - Since how long is the Shubharthi showing signs of schizophrenia?
    - Who is the treating psychiatrist of the Shubharthi?
    - Is the Shubharthi compliant for treatment i.e. is the shubharthi willing to accompany the caregiver to the doctor or ready to take medication?
    - What does the Shubhankar do?
    - Why did he /she decide to attend this training program?
    - What are his/her expectations from this training program?

Here the facilitator can say – "Friends we would like to know some details about you all, so that we will be in a position to understand your need of coming for this training. Please give us the following information while introducing yourself". Facilitator can write down the above points on the board.

The reasons stated for attending this workshop are written on board. Based on the responses given they are categorized into-

- To gain knowledge / information about schizophrenia.
- To learn how to work with your shubharthi.
- To understand how to manage emotions as caregivers.
- Other reasons.

"In this workshop we will be dealing with different aspects of understanding schizophrenia i.e. understanding symptoms, understanding the course of the illness, how is the onset of the illness, treatment options available and other relevant information about this illness.

Secondly, we are going to focus on different challenges that both, the Shubharthi and the Shubhankar, face on a day-to-day basis. We all know that our shubharthi can be very fearful and reluctant when it comes to socializing, continuing occupation, taking medication,

getting up in the morning doing daily chores etc. We will try to develop strategies in dealing with these day-to-day challenges.

Thirdly and most importantly we will be trying to develop insight into our own emotional world. We as caregivers are affected to a great extent while caring for our shubharthis. There are times when we feel guilty, sad, depressed, lonely, frustrated, anxious, angry and a lot more. It is very essential to understand our thought patterns and belief systems that are actually responsible for this emotional upheaval. And at the same time, it is essential that we learn/develop effective strategies to cope with our emotional problems.

Fourthly we will try to learn and understand effective communication styles. These styles will help us in effective communication and getting connected with our shubharthi.

Fifthly we will dwell on the significant issue of socialization and marriage of our shubharthi. We all know most of our shubharthis prefer to keep to themselves and find it very difficult to have age-appropriate socialization. What is the reason behind it? How can we help them socialize? What are their thoughts related to marriage? What it is that I 'as a caregiver feel about, he/she being married. All these aspects will be discussed in detail in the process of this workshop.

We will also try to answer or deal with any other issues that may be raised on the way which are significant and related to our topic.

Now let us first start with the question. Why involve caregivers in the treatment process or the important question which you all ask – Why do the caregivers need training?

- Friends let us understand the Indian scenario related to schizophrenia and caregivers, especially in cities and small towns.

- We see that most of the people stay in nuclear families today. They are away from their extended or joint family set-up. Maximum 4 to 5 members stay in one family.

- The caregivers are staying 24x 7 with the shubharthi. They witness all the ups and downs experienced in the course of the illness. They are aware of the symptoms experienced by the shubharthi.

- Shubhankars try their best to understand the condition of shubharthi caused by hallucinations and delusion. They try to help them deal with it in their own way. At times they succeed at times they fail. In the bargain the caregivers undergo tremendous amount of emotional stress.

- There are times when the caregivers are not exactly aware of what the shubharthi is going through. They are confused between the symptoms and the behaviour of the shubharthi. They find it difficult to handle the abusive, aggressive behaviour or violence caused by the symptoms of the shubharthi.

- Shubhankars have different roles to play. They have to manage their own occupation and also have responsibilities of different relationships. There are

times when they find it difficult to manage their different roles and duties. They feel burdened managing everything.

- Uncertainty of prognosis of schizophrenia takes a toll on the emotional life of the caregivers. As mentioned earlier they go through lots of emotional upheavals. They feel depressed anxious, angry, guilty, frustrated, hopeless. This process of chronic caregiving affects their physical and emotional health to a great extent.

- With the constant thoughts of "How will others in the social circle understand? What will they think about the shubharthi? Will they accept us?" etc. they isolate themselves and avoid mixing on social level. This loneliness adds to their emotional burnout.

- As the chronicity of the illness increases so does the age of shubharthi & shubhankars. It becomes all the more challenging to plan life ahead with lessening of energy and assets at hand.

In a nutshell let us understand why the caregivers need training ---

a. To understand thoroughly different aspects of schizophrenia including symptoms, course of illness and treatment.

b. To develop effective problem-solving strategies to handle day-to-day challenges experienced while dealing with the shubharthi.

c. To take charge of emotions experienced by you all and develop effective coping. It is also important to strengthen already existing effective and positive coping skills.

d. To develop clarity about the actions/decisions that need to be taken with reference to the future of the shubharthi.

e. To be connected with other caregivers and develop independent support system.

Till this point the facilitator should talk about, need for the training of the caregivers, family structure and different roles, challenges faced by the caregivers and what all will be covered in two days. All these points are to be described in brief to the group.

Now let us go on to the most important topic of "Understanding schizophrenia".

Now look at the following page:

Try to fill in your own thoughts and experiences and we can discuss this activity in the group.

YOUR PAGE : Activity 1

Some guidelines:

Note changes you observe in your Shubharthi from time to time.

When did you observe these last?

What did you do to address these changes?

How were you affected in the process?

What I observe is happening to my Shubharthi	My understanding of this as a sign of the process of the condition called Schizophrenia	The difficulties I face as I negotiate this journey with my Shubharthi in the context of this experience

Any other thoughts? Put them down here.

…….

……..

What is schizophrenia?

Schizophrenia means fragmentation of persons thinking and feeling process. Swiss Psychiatrist -Eugen Bleuler, coined the word schizophrenia in early 20th century. Schizophrenia is a thought disorder. This mental disorder interferes with a person's ability to –

- Think clearly.
- Manage emotions.
- Make judgments.
- Communicate.
- Recognize what is real.
- Perceive the world around appropriately.
- Behave appropriately.
- Insight about the illness.
- Maintain interpersonal relationships.
- Maintain touch with reality.

What is the prevalence and incidence of schizophrenia today?

Today more than 1.1% of the world population is affected by schizophrenia. Some studies place incidence at 1.4%. In other words, it means that 1 out of 100 people suffer from this disorder. In Indian scenario if we consider that there are 4 people in one family, then one family in 25 families is affected with this illness.

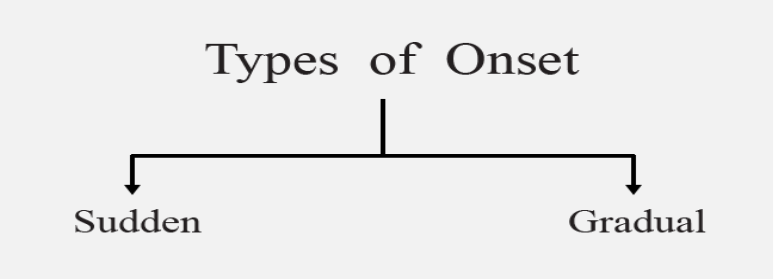
. Who is affected with schizophrenia?

Both males and females are equally affected with this illness.

- **When is the onset of schizophrenia?**

  Onset of schizophrenia in both males & females is observed around 15 to 24 years of age. These years are extremely important years of human development where the transformation from adolescent to an adult takes place. Schizophrenia affects the most productive years of human life cycle.

  IPH has done some work in this area, and you will find the studies in Manual 4.



Sudden onset is when there is a change in a person's behavior in 48 to 72 hours. Here the person suddenly starts experiencing hallucinations and delusions. Person may get aggressive and violent. Sleep deprivation can be observed.

Gradual onset is when the persons functioning is affected one by one over the period of 6 months to 2 years or more. Here the person may face difficulties in attention and concentration, socialization, managing emotions, personal hygiene etc.

Onset before 15 years of age is called early onset.

Onset above 40 years of age is called late onset. Late onset is common in females, which can be related to menopausal hormonal changes. But it is also seen in males.

- **How the person is diagnosed suffering from schizophrenia?**

Diagnosis of schizophrenia is considered by a psychiatrist only when the symptoms are present for 6 months or more. These symptoms can be seen for more than six months continuously or with repeated occurrences. It is important to have a proper history of the patient symptoms.

- **What is a relapse?**

When the symptoms recur, it is called relapse of the illness. Duration of relapse is varied for individual patients. There can be different reasons for relapse of the illness, like for e.g. some relapses are cyclical in nature i.e. they occur at particular time of the year or may occur every few years.

In some cases there can be various major stressors which can cause relapse for e.g. death of a loved one, major loss say financial or losing an educational year, or loss of a significant relationship. At times it is observed that relapse occurs when the shubharthi suddenly stops medication without consulting the doctor. These are few reasons why a relapse can occur.

- **How to prevent a relapse?**

Best way to prevent a relapse is having a detailed observation of the progress of shubharthi. Discussing the day to day happening with the shubharthi is very helpful. If there is any change observed or if symptoms which were absent are experienced again it should be taken as an alert. These symptoms should be rated on following parameters –

F = Frequency: (How often?)

How frequently the symptom is observed should be noted.

I = Intensity: (How strong?)

What is the intensity of the symptom? Is it affecting the day-to-day functioning of the shubharthi? Is it hindering the communication of shubharthi with others? Is that symptom causing lots of emotional upheaval to the shubharthi? These aspects should be observed and noted.

D = Duration: (How long?)

How long is the symptom experienced? Here time frame should be considered.

If there is increase in any of the above parameters for a time period of 4 days to a week, it should be immediately reported to the treating psychiatrist. Having a discussion with the shubharthi helps in understanding the symptoms.

Now let us take an example – If a shubharthi has started experiencing auditory hallucinations again, how to rate this on the above parameters.

Frequency:

How frequently is the auditory hallucination experienced by the shubharthi needs to be observed and noted for next two days.

Intensity:

Intensity of the auditory hallucination can be judged on two levels:

a) Does the shubharthi recognize that it is a hallucinatory experience and not real. Here the shubharthi will be able to ignore it & continue functioning.

b) Does the shubharthi feel that the hallucination is actual reality? In this scenario the shubharthi will start responding to the hallucination behaviorally or by answering to it. Here the shubharthi is unable to ignore it and his/her functioning will be affected.

Duration :

It needs to be observed how long does the hallucinatory experience last.

Making observation and notes of the above-mentioned parameters for say three to four days is essential. If there is increase in any of the parameter it is important to go and consult the doctor immediately. Reporting it to the doctor on time helps a lot. The consulting psychiatrist will immediately adjust the medication. Altered medication helps in arresting the symptoms and stops them from increasing their frequency, intensity and duration. This works as a major contribution in relapse prevention.

YOUR PAGE : Activity 2

Out of the symptoms discussed above which symptoms have you observed in your Shubharthi? Please list them down.

Also, try to list rate them on Frequency-Intensity- Duration parameter on a scale of 0 to 10, where '0' represents low/ less and '10' represents high/ severe.

0 ---------- 10

Low/less High/ severe

What I observe in my Shubharthi	How often it happens *(rate 1 to 10)*	How strong is the symptom? *(rate 1 to 10)*	For how long? *(rate 1 to 10)*

Persons who are not Shubharthis or Shubhankars find it difficult to understand how Hallucinations are experienced. What is the experience like? Could you please write down some personal examples you have been through with your Shubharthi, to help others understand? We understand this is hard for you, but please try to write what you can, and speak to your support group if it disturbs you.

…….

…….

…….

…….

…….

Understanding the Symptoms of Schizophrenia

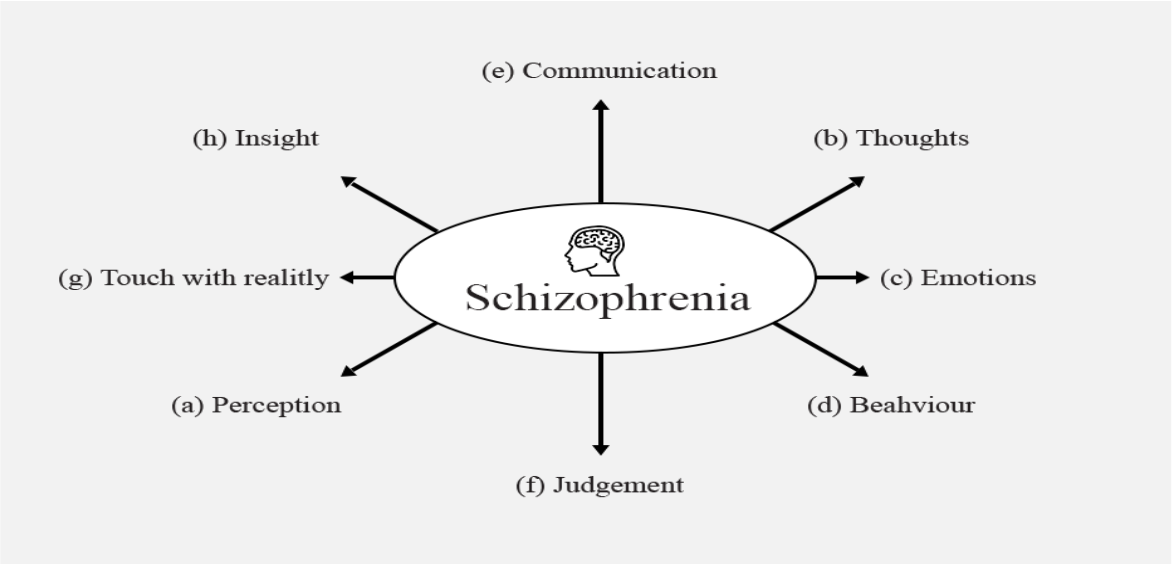
Here the facilitator says-

"I would like you all to give me a list of symptoms that you have observed in your shubharthi. I will write them down on the board. We will try to understand each and every symptom from a scientific perspective." The facilitator should ask each participant to give at least one symptom that they have observed. This will give the facilitator an idea of how much they know about the shubharthi's illness. Common symptoms that they give are.

- Hearing voices.
- Seeing things/people
- Suspiciousness.
- Withdrawal
- Lack of socialization
- Talking or laughing to self.
- Getting anxious.
- Anger outburst.
- Lack of proper hygiene
- Avoiding baths.
- Asking same questions again and again.
- Pacing
- Drinking tea (excessively).
- Smoking
- Excessive Sleeping.
- Laziness.

The facilitator should write the symptoms in different groups on the board. Then name each group based on the areas of functioning that are given below.

Friends now let us focus on understanding different symptoms of schizophrenia Pictorial depiction below will help you understand which major areas of functioning are affected when a person is suffering from schizophrenia.



In the diagram Socialization- interpersonal relationships/ attention, concentration and memory needs to be added

(a) Perception: We perceive our world through our five sense organs- eyes, ears, nose, tongue and skin. We see with our eyes, hear with our ears, smell with nose, taste with our tongue and feel the touch because of skin. Our shubharthis can experience hallucinations through any of these senses. Hallucinations are sensory experiences in absence of any stimulus. They hear, see, smell, or feel things when there is actually no stimulus. Shubharthis hear voices of different people, see people or animals or Gods or demons or anything else, they get different smells, food taste differently or may feel that something is crawling on their skin. It is very important to understand that these experiences are not shared or experienced by anyone else around. These hallucinatory experiences generate a range of emotional and behavioural responses in the shubharthi. For example, if they hear someone talking, they respond to those voices or do whatever the voices tell them to do. These hallucinatory experiences can trigger behavior that can be injurious to the shubharthis or others.
(Here the facilitator can give more examples of hallucinations & hallucinatory behavior).

(b) Thoughts: Schizophrenia is a thought disorder. People suffering from schizophrenia get lots of thoughts. Speed of theirthoughts is also very rapid. Many times, thoughts are not linked to each other. Because of such pattern of thoughts, they appear to be lost in their own world or at times get very restless. We as caregivers never understand what types of thoughts, they get but the end result is seen in their behavior that they are restless, or lost in their own world. Many times, their face appears expressionless.

On thought level our shubharthis can experience different types of delusions. Delusions, are strong beliefs or ideas without any baseline proof. There can be different themes to their

delusions. For example, suspiciousness about someone being against him/her, someone plotting against him/her, people developing a network to trouble him/her in different ways, people trying to lace their food with poison etc. Another type of delusion can be related to self- image where they believe that they are God or messenger of God or some historical figure or some very important person. At times some delusions can be in the form of a belief that he/she is not appearing like a normal human being, or there is some growth on the body or so.

Sometimes delusions can be related to the spouse that he/she is having an extramarital affair with someone in general or specific.

At times the shubharthi believes that someone is in love with him/her and will be totally lost in those thoughts.

Shubharthis complain that people outside can understand their thoughts or know what they are thinking. In some cases they strongly believe that their thoughts are transmitted via TV or radio.

Our shubharthis get thoughts which

1. may not be based on reality,
2. may not be linked to each other,
3. may be repetitive,
4. may generate a range of emotions like fear, anxiety, anger, sadness.
5. may be quantitatively excessive but qualitatively poor.

This type of thinking tires our shubharthi to a great extent. Caregivers needs to understand that this mental fatigue can be very draining to the shubharthi. Hence many a times they appear to be withdrawn, and prefer to keep to self and not interact or talk with anyone.

(c) Emotions: Emotions are the core part of human existence. We human beings feel and express a different range of emotions. But friends our shubharthis are not so lucky. They find it extremely difficult to feel and express emotions as others do it. It's a major challenge for them to experience emotions and express it through verbal or non-verbal communication. Now let us pay attention to some symptoms that are observed in our shubharthis say – blank face, lack of expression, sudden crying, feeling anxious, anger outburst, mood swings, lack of communication with others etc.

Let us try and understand why they experience these symptoms.

Firstly, as we know that they are lost in their own thoughts, so many a times they appear to be expressionless. Secondly these thoughts can have different themes which can generate anxiety, depression, fear, anger or any other emotion. The facilitator motivates the group to think by giving a scenario and helps them generate possible reactions. Let's take an example. Our shubharthi Mahesh (name changed) has constant thought that the neighbours are

plotting against him and spreading negative information about him in the complex/ society. What emotions will he experience when –

a. The neighbouring aunty comes to his house and starts talking to his mother – Yes, he will feel suspicious, angry, about the mother – His possible thoughts will be why did my mother talk to the aunty- did they talk bad about me? – so he will feel very angry towards his mother and may shout at her.

b. He sees from his window that the neighboring uncle is talking to some other people in the complex. They are standing in a group of three and having a discussion about some issue. They are looking here and there and happen to look at Mahesh's window. How will Mahesh feel? He will feel anxious, fearful. Because his thought would be that neighboring uncle is telling something bad about him to others. Now they would tell about him to other people. These thoughts would make him all the more fearful.

Our shubharthis cannot channelize their thoughts and impulsively tend to react. In some cases, they are so engrossed in their own thoughts that even if something positive is happening, they fail to acknowledge it and react to it or just give a bare minimum reaction.

There are some shubharthis who are suffering chronically for more than 25-30 years. They are on medication for a long time and the caregivers very commonly report that they are most of the times expressionless or in clinical terms we call it having "blunt affect". This can be experienced while watching TV, chatting, reading, listening to their favorite songs etc. We all observe that their expression is very limited or there is no expression. Even if they express, their tone is flat and hence we caregivers find it difficult to understand what they are exactly feeling.

I would like to share my experience with you all. As I mentioned earlier we have our rehab day care workshop 'Tridal'. Nearly 25 shubharthis come daily to our workshop and work together. I don't regularly go to Tridal. Whenever I go many of them welcome me with a smile or say "How are you madam, came after a long time?" Some even ask me about my son and other family members. My observation is that, some smile to me and ask something, some shake hands, some ask but don't maintain eye contact, some have a flat tone… I know they mean what they ask but their expression differs. We caregivers have to believe in the humanness in them. They as human beings feel and understand like others but may lack appropriate expression. We have to communicate with them appropriately and become their role models. We also need to understand that they have limited scope of learning due to few social interactions. If the people who are around them – their family members, volunteers at the rehab workshop like Tridal, are appropriately and effectively expressing and communicating with them and with each other they will learn to express better.

Many of our shubharthis also experience "anhedonia" which is inability to feel happy or experience happiness. There is a constant phase of amotivation or inertia because of

which there is lack of proactivity and initiation of any activity. This is also a type of negative symptom which becomes challenging to deal with.

(d) Behaviour: "I would like to explain this functioning with an example –Medha is a 29 years old, unmarried girl, staying with parents. She is suffering from schizophrenia since last 10 years. Now she has this strong belief that someone outside the window is keeping a watch on her. What will she do? (Here the facilitator will ask the group to respond). Most common responses will be – go and check the window, draw the curtain, close the window etc.

Now she has a further belief with visual hallucination that someone has put a camera in their bathroom, what will she do? (Facilitator encourages the group to think of different responses). Expected responses will be – She will close the bathroom door, stop using the bathroom, stop taking bath, will not get out of the room etc.

Now understand in both these scenarios any of this response can be observed. As caregivers it is extremely crucial to understand that you will always see the end result in her behavior. That is, you will see her closing the window or skipping bath for 2/3 days.

When the caregivers coax her, she may spell out her thoughts otherwise they will have no clue to why she is behaving in a particular way. Caregivers also tend to report to the doctor only about that observed behavior.

In the previous example the caregiver will see that Mahesh is angry because the neighboring aunty spoke to his mother and he may start sulking, getting snappy, not co-operating with the mother, or even shouting. If the mother is well aware of his delusion about the neighbor, she will be in a position to understand his behavior, otherwise she will have no clue about what is happening to him, or why he is reaching angrily?

Few other observations of behavior mentioned by in our symptom list were pacing, doing things impulsively and speedily, drinking excessive tea, asking same questions repeatedly, sleeping excessively. Some of these like pacing can be the side effect of medication. This needs to be clarified with the doctor in the follow – up visit.

Asking same questions repeatedly can be because of boredom or obsessive thinking.

It is important to make a list of these observations and rate it on F-I-D parameter scale mentioned earlier. This will help the psychiatrist to get a better picture of the symptoms. Also having open communication with the shubharthi as and when the shubhankar can, will be helpful.

(e) Communication: Human beings' function by communicating with each other. This communication can be verbal and non-verbal.

Verbal communication consists of words used, tonal quality and speed of talking.

Non-verbal communication involves facial expression, body language and eye contact.

A communication is effective when the person uses appropriate words, clear voice, and proper tone, maintains eye contact and has congruent facial expressions. Synchronizing all these aspects which are very normal and natural to humans can be very challenging to the shubharthis. We all have observed that they fail to maintain proper eye contact. The words they say can be at times very loud or at times hardly audible to others.

Poor eye to eye contact, monosyllabic conversation, not taking part in group conversation, keeping to self, can be few examples of problem or challenges in communication.

(f) Judgement: People suffering with schizophrenia have difficulty with making appropriate judgements. For example, they may dress inappropriately, at times may ask inappropriate questions or say something out of context. Ability to comprehend social situation and behave appropriately is social judgement. Many times, our shubharthis lacks social judgement.

When in active phase of their illness our shubharthis are troubled by hallucination and delusions. It is observed that their judgment and following behavior is colored by their hallucinations and delusions. Let us go back to our example of Mahesh and his delusion about the neighboring family. Now he may get angry if he sees that his mother is talking to his neighbor or at times in his anger, he may say something inappropriate to them. In such situations it becomes difficult for the caregivers to convince the shubharthi.

(g) Touch with reality: Due to the hallucinations and delusions that the shubharthis experience, it becomes difficult for them to stay in touch with actual reality. This reality is the one that is experienced by other family members or rest of the significant others. In Medha's case we can very clearly see this difference. She has a belief that cameras are installed in her room and bathroom. She actually sees the cameras in form of "visual hallucinations". These hallucinations are not shared by other family members. According to all of them, there are no cameras present. Here her stopping from using the bathroom or her room are the result of her hallucination. This is where she goes away from the common reality experienced by others in the family.

Closing all doors and windows of the house. Not taking food cooked or served by anyone else are few signs of lack of touch with reality.

(h) Insight: Insight is the understanding of the condition, what is exactly happening to self. There are different types or levels of insight. One level is ‘Intellectual Insight’ where the Shubharthi is aware that something is wrong with him/her. He/she is unable to function like other people of the same age group. Shubharthi is aware of the symptoms including hallucinations and delusions. They show readiness to take medication to get relief of the symptoms.

Emotional Insight - It is the Shubharthi's ability to understand and accept that 'I am suffering from a condition called schizophrenia and it has posed some restrictions on my level of functioning'. For example, if the Shubharthi was very good academically before the onset, may gradually or suddenly deteriorate academically after the start of the illness. Here the Shubharthi will have emotional insight when he/she accepts that it is difficult to pay attention & concentrate as earlier and hence may not perform up to the earlier level of academic achievement. Accepting this and resetting educational goals will be the key to restore the functioning level of that Shubharthi.

Fluctuating Insight is observed when a Shubharthi swings between acceptance and non-acceptance of the illness. When the Shubharthi is not ready to accept the illness, his/her compliance with the treatment process will be very poor.

Friends point to note here is that the way we see levels of insight with Shubharthi, similarly insight of the Shubhankars is also very important. They also tend to have similar levels of insight. Extremely good emotional insight by both Shubharthi and the Shubhankars is necessary for good prognosis of schizophrenia. Getting frustrated over academic failure after relapse can be one sign of lack of emotional insight. Accepting that it is not a good time to get promoted after a long fight with symptoms and then gaining stability is a good sign of having both intellectual & emotional insight.

(i) Maintaining Interpersonal Relationships: Our Shubharthis many a times find it difficult to relate to people. This can be caused by poor emotional expressions or different thoughts, prejudices, delusions they have about other people. Even in the family they may be selective about whom to communicate with and when. Due to excessive thoughts which are mostly of poor quality, they have very less to communicate. They talk in monotone, repeatedly ask same questions & avoid maintain eye contact with others. As a result even other people are less interested in communicating with the shubharthis.

(j) Socialization: It's a natural human tendency to socialize. Shubharthis are very apprehensive about socialization. This happens mainly because on one hand they don't know how to communicate effectively. On the other hand they lack age appropriate functioning which makes them feel inferior. They don't have answers to questions like "What are you doing?", "Where are you working?", " When will you get married? " etc. Anticipating such type of questions, they avoid socialization. Thirdly if they have active paranoia, containing "people are talking about me, looking at me, staring at me," going to any social event is going to cause a lot of anxiety and insecurity. Hence, they prefer sitting at home and isolate self.

(k) Attention, concentration and memory: People suffering from schizophrenia very commonly complain of poor attention, concentration and memory. This happens primarily because Shubharthis get excessive thoughts. These thoughts interfere in whatever activity they are doing. For example, if the shubharthi is reading they lose track of what is being read once they drift in their thoughts. Paying attention and concentrating becomes very

challenging. Further what is read is not understand properly a registered which makes the memory weak.
Let us take another example. Neha is presently studying in her twelfth grade. Her hallucinations and delusions are under control with medication, but uncontrolled thoughts are present in the background. When she is attending her lectures, she can pay attention to the topic for 15 to 20 minutes, but later it becomes challenging as her thoughts keep on troubling her. She misses major part of what is taught. Because Neha is unable to pay proper attention, she cannot comprehend what is taught completely. As there is lack of comprehension, she cannot store it in her memory. As a result, retrieving the content becomes a challenge.

Positive & Negative Symptoms-

Symptoms can be further classified into positive symptoms and negative symptoms. Positive symptoms are those experiences which are added to the person's psychological world like- delusions, hallucinations, bizarre behavior, fragmented thinking, anger outburst, poor sleep etc.

Negative symptoms are those which take away certain aspects which are necessary for a person's normal day to day functioning. For example, blunted affect, loss of interest & motivation, social withdrawal, indecisiveness, poverty of thoughts, excessive lethargy, poor communication, lack of personal hygiene etc.

Please read through the case study given on the next page carefully.

This is not a test. It is just an effort to make sure we are all on the same page, and we all understand this phenomenon that is called Schizophrenia by psychiatrists and mental health professionals.

Our experience with our Shubharthis has made us very aware of these changes in our family member. Let us jot them down so that they can help others.

YOUR PAGE Activity 3.

A case study.

Pratibha is 27 years old. She has completed her graduation in commerce 6 years ago. When she was doing her T.Y. B.Com, she started experiencing problems in attention and concentration, her sleep was disturbed and she used to frequently get irritated. She felt that her friends in the group have started avoiding her because they went for a movie without her. She stopped talking to them. Her friends used to come home, but she was not ready to interact with them. Her final exams were approaching and she stopped going to college, but continued going to the tuition classes. She somehow managed to give her exams and got a second class. After her exams she went with her parents to her native place. Pratibha's parents observed that she has gradually started keeping to herself, at time muttering something or talking to self. When they enquired, she said that she was chanting some mantras to drive away the evil. After few days they returned to Mumbai. Her parents were worried for her as she used stay awake the whole night and say some prayers. Her food intake reduced significantly. She started fasting every alternate day. When asked, she would say that if she doesn't follow these austerities the demons will destroy her family. They talk to her and warn her about the doom that can come on her family. Only her prayers can help her family is what she strongly believed. Once she prayed for three consecutive days and night, without sleeping, eating, taking bath or coming out of her room. On fourth day she fell unconscious and was taken to the hospital. Psychiatrist was consulted and treatment was started. She recovered from the symptoms after the treatment. Her sleep was restored, she started eating, taking bath, talking to the family members. The demons stopped talking to her. She was happy that her prayers saved her family from any harm.

She decided to stay unmarried and guard her family. Pratibha stopped her medication after two years as she was feeling better. Now she was not scared of demons threatening her to harm her family. Her praying had also reduced significantly. Few weeks after stopping her medication she again heard the demons talking to her. Her thoughts increased, she could concentrate on any activity and became very fearful. She stopped going out because she was worried that something will happen to her family. Excessive praying was observed along with lack of sleep and self-care. She was admitted to the hospital and medication was stared. This time ECT's had to be given along with medication.

Pratibha today works as a part-time clerk in a departmental store. She has a very strict disciplined schedule since morning which involves doing pooja and prayers. She gets very upset if her routine is disturbed. She is presently taking medications and no active symptoms are seen. She lacks socialization, or hardly interacts with anyone in the house. In office, Pratibha's interaction with people is limited only to work related issues. Pratibha has one elder brother and elder sister. Both of them are married. She hardly has any interaction with them.

Questions based on the case study:

- What are the symptoms that Pratibha experienced?

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- What are the positive and negative symptoms experienced by Pratibha?

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- What type of hallucinations does she have?

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- What is Pratibha's delusion?

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- What treatment was given to Pratibha?

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Here are some pointers that will help you in your journey with the Shubharthi

- *Early warning signs*

Changes in behaviour, lack of interest in day-to-day activties, sudden mood swings, possible hallucinatory experiences, problems in academic or occupational adjustment can be considered as some of the early warning signs. It is also important to note the age of onset of the symptoms.

- *Importance of early intervention and treating first episode psychosis (FEP)*

Understanding and treating the symptoms early is a major contributor of a good prognosis in the recovery of schizophrenia. Early intervention helps to restore the shubharthis functioning quickly and reduces the harm that it can cause to the development and growth of the person. It is seen that early intervention is a key for good prognosis and overall life stability of the shubharthi.

- *Picking up early signs of relapse.*

It is extremely beneficial when the Shubharthi and the Shubhankar have a good and proper understanding of the symptoms of schizophrenia that he/she has had. This understanding helps is picking up any small changes in mood, behavior or thoughts. Experiences of hallucinations or any other symptom can be rated on Frequency-Intensity-Duration paradigm and immediate action can be taken. Consulting the psychiatrist immediately after some changes are observed helps in prevention of relapse. Another strategy can be meeting the mental health professional anticipating the challenges in near future and sdjusting the dose before hand can also be helpful. For eg. If there is an upcoming marriage or any other social event where participation of the shubharthi is significant, developing coping strategies beforehand with help of the mental professional can avoid relapse.

Treatment of schizophrenia:

We have very clearly and in detail seen the symptoms of schizophrenia. In this process we have tried to understand what areas of day-to-day functioning are affected due to these symptoms.

Now let us go a step further and understand what treatment option are available for the person suffering from schizophrenia.

There are three broad ways in which schizophrenia can be treated.

a. Pharmacotherapy.
b. Psychotherapy.
c. Rehabilitation.

(a) Pharmacotherapy:-

Pharmacotherapy includes medication and injections given to treat symptoms of schizophrenia. The medicines used to treat schizophrenia are called antipsychotics. Antipsychotics are medicines, which work against the psychotic symptoms of the shubharthi. The anti-psychotics block the receptors of the neurotransmitter dopamine in the limbic system of the brain. The anti-psychotic medication has some side effects. Earlier anti-psychotics helped in reducing only the positive symptoms, but today specific medication is available to treat the negative symptoms also. These new anti-psychotics also have lesser side-effects. The anti–psychotic medication is in form of tablets or liquid drops. These are supposed to be taken orally or at times given in the food when the shubharthi is non-compliant. Depending on the symptoms along with antipsychotics, anti depressants or mood stabilizers or anti OCD medication may also be given. Any doubt about medication should be clarified with the treating Psychiatrist.

Injections: Anti-psychotic injections are given in two ways – Intravenous and Intramuscular. Intravenous injections are given mainly when the patient becomes violent, aggressive or has acute positive symptoms. Intramuscular injections are given once in a week, 2 weeks, 3 weeks or a month or 6 weeks as per need. They are called depot injections, as the medicine injected is stored in the muscles and work on the principle of slow release. This is given to chronic patients and to the patients who have tendency to avoid medication. This also helps in relapse prevention, in reduction of positive symptoms like hallucinations, delusions and also to reduce the associated symptoms such as agitation, impulsiveness and aggressiveness.

Electro Convulsive Therapy (ECT): Electro Convulsive Therapy (ECT) is called 'Shock treatment' in local terms. Choice of giving ECT is considered when the shubharthi is either injurious to self or others. In other scenario when medication is not giving desirable effect ECT's are given. Caregivers are supposed to sign a consent form before the ECT is given. The course of ECT's can have 6 to 12 ECT's given over three – four weeks. This will depend on the condition of the shubharthi and his response to the initial ECT's.

ECT's are given under general anesthesia. Shubharthis are supposed to stay empty stomach atleast 4hours prior to the anesthesia. Along with the anesthesia muscle relaxant is given to avoid any complications. ECT's are given with special electrodes. These electrodes have two ends, which are cushioned to avoid burn marks. Special jelly, which is a good conductor of electricity, is applied to these ends. They are placed on the temples on the forehead and a mild current is passed for 10 to 15 seconds till a twitch is observed in the feet of the patient. This is called Electro Convulsive Therapy because an artificial convulsion is created with the help of the electric current.

We need to understand that ECT's are not a replacement to the medication or pharmacotherapy. The patient has to take medication even if he/she is given ECT's. ECT's are safe as they are given by psychiatrist with utmost precaution and in the presence of anesthetist. Many people are scared of ECT's or have misconceptions about ECT's because of the way media portrays it. It is extremely important to clarify your doubts with your

treating psychiatrist and avoid discussing it with any lay people which can cause more confusion.

Side Effects of Medication: Given below are few side effects of medication commonly observed-

- Pacing, restlessness, inability to remain at one place, inner unrest and an urge to move is observed.
- Shubharthis are unable to sit at one place, march on the spot or put hands in and out of the pockets.
- There is lack of normal spontaneity and energy. Shubharthis become slow to respond.
- Dryness of mouth which can affect speech to some extent.
- Constipation.
- Trouble in urinating.
- Blurry vision.
- Confusion.
- Movements of lower jaw (writing movement), movements of tongue or hands is observed.
- Stiffness or rigidity in face, neck, limbs or body is observed.
- Tremors in hands or body are seen in some shubharthis.
- Shifting gait, postural instability, blank face are commonly observed.
- Males may experience sexual impotency or failure of ejaculation.
- Menstrual irregularities can be experienced by females.
- Some shubharthis may feel sedated and sleep for long hours.
- Few anti-psychotics can cause weight gain.

It is extremely important that the caregivers ask the treating doctor about the possible side-effects of the medicines that they prescribed. This clarity will help in understanding any changes in the shubharthis behavior, and can reduce anxiety of the shubharthis and the caregivers.

At times one has to weigh between the symptoms experienced and the side-effects. If the symptoms are hampering day to day functioning to a great extent and are also injurious to the shubharthi or others, then the effects need to be addressed in a different way. For example, if constipation is the side-effect, then increasing fiber intake in the food is advisable, if dryness of mouth is experienced then sipping water at frequent intervals or chewing some lemon or orange sweets recommended. It is important that proper observation of the side effects should be done and measures to avoid it need to be worked with the psychologist, therapist and psychiatrist.

(b) Psychotherapy & Counseling:

Individual and family counseling is extremely essential for developing insight in the shubharthi and shubhankar. In the Indian scenario we commonly see that the treating psychiatrist is unable to give sufficient time to the clients and caregivers. Shubharthis have many questions related to illness, which are left unanswered. This gap is very effectively filled in by the clinical psychologist, social worker or a counselor.

These sessions can focus on giving psycho-education to the family where the psychologist will discuss about the symptoms of that shubharthi and the limitation that it can cause. These sessions can be helpful in developing both intellectual and emotional insights.

Discussion in these sessions can help the shubharthi develop social skills and communication skills.

These sessions can be of help to the shubhankar in relieving their stress by venting out and developing effective coping strategies.

In these sessions the caregivers can redefine their expectations from the shubharthi on a much more realistic level.

Hence counseling along with pharmacotherapy is very helpful and extremely necessary.

The treating psychiatrist will indicate when the shubharthi is ready for the process of counseling. The caregivers can independently start their counseling process even if the shubharthi is unwilling to undergo counseling.

In a nutshell counseling helps –

- in developing intellectual & emotional insight of both the patient and the caregivers.
- in developing effective communication and social skills of the shubharthi.
- in developing healthy coping strategies for both shubharthi and shubhankar.
- the caregivers to talk about their stressful issues and workout coping strategies.
- the shubharthis to redefine their occupational and personal goals and develop strategies to achieve it.
- the family to have effective and smooth functioning.

(c) Rehabilitation: -

Rehabilitation is necessary for the shubharthis who are low functioning or totally dependent on their family to fulfill their basic needs. Depending on the condition of the shubharthi the treating psychiatrist will recommend which type of rehabilitation is required. One type of rehabilitation will be where the shubharthi will be institutionalized for a period of two to three months. This is needed for the patient who is totally low functioning.

Another option is like a day care which the shubharthi will attend the rehabilitation center daily for fixed hours. Here the shubharthi is taught different skills and works on various activities like stitching, making paper bags, making decorative items, trying their hand at kitchen work, gardening etc. Going to a rehabilitation center gives them a chance to develop their social skills and communication skills. This also gives them a chance to work in a team and set and achieve targets.

In India Institutional facilities are not easily available. Some institutions which are available can't be very affordable to common people. In such scenario it is advisable that the caregivers come together and with the help of the mental health professional start a day care facility. Our rehab facility Tridal was started similarly as the need was felt by a group of caregivers and professionals to do something for the non-functioning shubharthis.

Important Note: -

It is advisable that the sections of

a. **Treatment of schizophrenia.**
b. Causes of schizophrenia.

are taken by a consulting psychiatrist in the caregivers training. This will help the caregivers to authenticate this information and ask questions if any. If a psychiatrist is not available then a trained clinical psychologist or psychiatric social-worker can handle this part. Impart the information only that is given in this module. Don't add any here-say non-scientific information. If the psychologist or social worker is unable to answer any question related to this topic please admit it openly. Encourage the caregivers to ask the question to their treating psychiatrist. Avoid commenting or giving information of the topic that you are not sure about.

Causes of Schizophrenia:

We all as caregivers are very eager to know, to find out what caused schizophrenia to our loved one. We lose our sleep thinking about the reason what exactly went wrong and why our loved one is suffering. We blame self and others for different things done or not done. Even other people in the family don't leave a single chance to blame us as parent as a cause of this illness. We also try to link out the reason to God and his/her curse.

Today let us find out what is the scientific reasoning behind the cause of schizophrenia.

Let us try and understand the causes of schizophrenia from two angles: The factors that can be called as "**Causative**" and factors that can be called as"**Contributory"** to the happening of this illness. Causative factors are the factors which are observed in all the people suffering from schizophrenia across the globe. Contributory factors are the set of factors that can be different for each shubharthi.

Causative Factors:-

a. Neuro-Chemical Imbalance: - Brain has control over all our bodily functions like breathing, maintaining temperature of the body, bowel movements, bladder control, blood flow, heart , kidney functions etc. Similarly brain also has a major role in our thinking, emotion, perceptions, attention, concentration, memory, etc. Different centers of the brain are responsible for different functions of humans. This functioning is based mainly on the neuro-chemical secretions in these centers. When there is an imbalance in this secretion it results in problems in the functioning. Imbalance in the secretion of neuro-chemicals like dopamine in the synaptic sites causes symptoms of schizophrenia. Medical science today has not yet found the reason for the cause of this imbalance. There is a deficit observed in the brain activity after this imbalance. The brain responds to different signals in the environment and lacks ability to screen out unwanted stimuli. Some stimuli are misinterpreted.

Contributory factors: -

- **Heredity:** Heredity is one of the strong contributory factors of schizophrenia. Children who have both or either of the parent suffering from schizophrenia, have a high risk of getting schizophrenia. Similarly, if any of the grand-parents or first relatives are suffering from schizophrenia or any other psychiatric illnesses, children in these families have risk of getting schizophrenia or any other psychiatric illness.
  It is also worth noting that even though there is no incidence of schizophrenia in the earlier generations still anyone can suffer from this illness. This shows that heredity can be a contributing factor and not the cause of schizophrenia.

- **Neuro-developmental hypothesis:** Neurodevelopment of the foetus in the womb is considered very crucial for normal development of a human being. Any pathological process occurring during this period can contribute to the dysfunctioning of a person in later life.

- **Birth trauma**: Normal birth history is very important for normal human growth. Any complications during child birth can cause injury to the brain. This can contribute to the happening of schizophrenia or any other psychiatric illness.

- **Change in brain structure:** It is observed that the brain of the person suffering from schizophrenia is smaller in size as compared to average human brain. There is a decrease in size of a temporal lobe. Temporal lobe processes sensory input and makes it possible for a person to develop new and appropriate behavior. We see our friends suffering from schizophrenia lose their judgment and behave inappropriately in different circumstances.

SECTION II

Handling day-to-day challenges while dealing with the Shubharthi

Day to day challenges experienced by the caregivers

All caregivers would agree that living with a person suffering from schizophrenia can be very challenging and stressful. Nobody can be blamed for it. The chronic and severe nature of the condition causes challenges on day-to-day level to the caregivers. Caregivers experience challenges on a day-to-day basis. Many a times they are left alone in this battle and feel lonely. We as a group will try to understand different challenges faced by the caregivers and develop strategies to deal with it.

The facilitator says – "Please share at least one problem that you as a shubhankar face while caring for the shubharthi. We will make a list of the problems and find out strategies to deal with it.

Facilitator will jot down the problems stated by the caregivers on the board. Possible problems shared by the caregivers are as follows.

- Shubharthi's reluctance to take medication.
- Shubharthi refuses to go to work/school or college.
- Shubharthi starts talking about his/her delusions and hallucinations.
- Shubharthi getting aggressive and violent.
- Shubharthi gets irritated or angry easily, or has become argumentative.
- Shubharthi refuses to attend social gatherings
- Shubharthi avoids guests at home.
- Shubharthi gets up late in morning / sleeps throughout the day.
- Shubharthi refuses to take bath.
- Shubharthi asks questions repetitively.
- Shubharthi cries easily.
- Shubharthi lacks motivation and interest to do any work.
- Shubharthi indulges in frequent tea and tobacco consumption.
- Shubharthi has problem in attention and concentration.
- Shubharthi paces up and down the room.

F-I-D of symptoms.

We have made an exhaustive list of the problems faced by the group. Now to start with each problem faced by the shubharthi is to be classified under the following important parameters:-

- **Frequency:** How frequently does the problem occur?
- **Intensity:** How intense is the problem? Has the intensity increased?
- **Duration:** How long does the problem last? Say minutes or hours.

These are the same parameters that we have used to rate the symptoms shown by the shubharthi. All the problems can be rated on these three parameters or any one of them.

Now let us take an example – if a caregiver says that the shubharthi is talking to self. This observation has to be rated on above three parameters. Before that the caregiver should note if this problem was observed newly or was present earlier. The caregiver should take a time frame say of 2 days or 3 days and make note of –

a. Frequency - How frequently is the shubharthi talking to self?

b. Intensity - How is he talking, are there hand movements, how is the quality & tone of voice, what are his emotions while talking?

c. Duration - For how long is the shubharthi talking to self? Say how many minutes or hours. Does it last for a longer time?

If answer to any one of the parameter is 'yes' then it is important to further keep track of it and also of any other changes in the behavior. If the answer to all the three parameters is 'yes' then it is better to immediately meet the consulting psychiatrist. This is the way you have to deal with different problems you encounter in handling the shubharthi. It is of great help if the shubhankars make a proper list of the problems that they face. Some problems may be experienced for a particular period and then may go away on its own. Making a note of when the problem is observed and when it is absent is always helpful. This can give us the pointers or the variables which can be causing the problem and if it can be avoided. Now let us look into the problems that we have listed on the board and develop strategies to deal with it.

1. **Shubharthi's reluctance to take medication:**

Medication has a significant role in the recovery process of schizophrenia. When shubharthi lacks necessary insight of what is happening to him/her, compliance to the treatment is the first casualty. Shubharthis refuse to take medication mainly because they feel that nothing is wrong with them. They may frequently skip the doses. It is important that the caregivers regularly supervise the medication, keep track of the strips and tablets. Check how many doses are taken and how many are left, especially if the shubharthi is taking medication on his/or her own. If the shubharthi has a tendency to forget or avoid medication inform the doctor. Anticipate the situation and take guidance from the doctor about it. Most of the times treating psychiatrist will give alternative prescription of transparent medication,

i.e. tablets or drops which can be given to the shubharthi. These medicines are odourless, colourless and tasteless so it can be easily mixed with the food and given to the shubharthi without his/her knowledge. Try to convince the shubharthi to take medication regularly but avoid getting into major arguments over it. If the shubharthi is totally reluctant to take medication it is better to take guidance from the doctor.

2. **Refusal to go to work or college/school:**

When this problem arises the family members need to be cautious. Here the parameter of frequency is very important key to understand the significance of this observation. First note how frequently the shubharthi has not gone to work, or he/she doesn't feel like going. It is also important to note if the shubharthi has started returning early from office or is bunking lectures in college. Have a discussion with the shubharthi. This discussion should yield information about following issues.

a) Is there any change in the work/college environment?
b) Is there any change in the job profile?
c) If in college, are there any upcoming submissions, project presentation or exams.
d) Is the shubharthi experiencing any hallucinations and/or delusions when at work/college?
e) Is there any problem between the team/friends that has arised recently?
f) Is the shubharthi finding it difficult to work or concentrate on work/study and is making mistakes?
g) Is the shubharthi taking medication regularly?
h) Is there any incidence of bullying in the college?
i) Is the shubharthi reprimanded for any reason in his/her office?

It is extremely important to have proper discussion on above mentioned issues or any other related issues. This will give an idea of what is exactly bothering the shubharthi. Taking the shubharthi in confidence and discussing the problem helps. Dialogue can be initiated by saying -

> *"I know that you are making efforts to go, but I think something stops you from going. What is it? Would you like to share it with me? Let me see if I can help you in any ways".*

One must remember that scolding the shubharthi or screaming is of no help. Even after initiating the conversation, showing willingness to understand the problem the shubharthi may refuse to talk or stop going to work or college completely. Again, scolding or having arguments with the shubharthi is of no use. It is better to go and have a word with the treating psychiatrist to get a breakthrough.

In some cases, talking to the shubharthi's friend or colleague can help. But this has to be done very cautiously keeping in mind that shubharthi will be going back to the same

office or college. If the information source (i.e. friend or colleague) is taken into confidence and informed about the condition of shubharthi he/she can share their observations to the shubhankar. They can also work as a good support to the shubharthi when he/she joins back. These people can be those with whom the shubharthi is otherwise comfortable and close.

3. Shubharthi starts talking about his/her hallucinations or delusions:

It is very challenging when our Shubharthi starts talking about his/her delusions. Shubharthi is very much convinced that it is real and we as caregivers just can't believe it. Now what is to be done in such situation? First and fore most do not argue or force your understanding and logic on the shubharthi. Try to put yourself into his/her shoes and understand what emotions he/she is experiencing. For example, to our friend Medha who is sure that there are cameras put in her bathroom you can say *"you must be feeling very scary, anxious when you see cameras in the bathroom".* This reflection of her feelings will make her realize that you are attempting to understand what she is experiencing. Being non-judgmental, unbiased towards shubharthi's experience is necessary. It is important to remember that these hallucinations or delusions are real to him/her as your experiences are to you. Rate the frequency-intensity and duration of this experience. It is important to check if the shubharthi feels it is reality or just an experience. Here Medha can get a thought that there is a camera in her room or very confidently say that there is a camera put in her room. If it's just a thought she will continue to use the room but if she is confident that the camera is in the room, she will not enter the room. The resulting behavior is also important and needs to be observed. If there is increase in F-I-D or any one of the parameters report to the doctor immediately.

4. Shubharthi getting irritated and angry:

Getting irritated and angry is commonly seen with people suffering from schizophrenia. At times the reason can be trivial. As seen while understanding the symptoms our shubharthi finds it difficult to regulate emotions. It is important not to argue or fight with the shubharthi when he/she is angry. Try talking to him/her later when he/she has calmed down. Brain storm with the shubharthi other alternatives of expressing his/her feelings so that anger outbursts can be avoided. Request him/her to discuss the problem with you or someone else before it escalates. Sudden increase in F-I-D of anger should be reported to the doctor. Also check if the medication is taken regularly. If the Shubharthi is working or studying it is good to check if there are no new stressors in office or college.

5. Shubharthi getting aggressive and violent:

At times shubharthi finds it extremely difficult to regulate his/her emotions or process his/her thoughts which can result in sudden aggression or violence. Caregivers are stunned and scared with this behavior and are totally at lost to handle it. At times there can be breaking of things in house or even throwing things. In such scenario the shubhankars are compelled to take help from the neighbors or other people. This can be very embarrassing to everyone. If the shubharthi has a tendency to get violent it has to be discussed with the

treating doctor beforehand. The caregivers need to know of any medication to be given to the shubharthi immediately in such circumstances. Gradual building up of anger needs different strategy as discussed earlier. Sudden aggression and violence need immediate medical attention.

6. Shubharthi refuses to socialize:

Refusal to attend family get-togethers or social functions is common with people suffering from schizophrenia. There can be different reasons for not mixing up with people. It is important to understand why they are avoiding meeting people.

a. Is it that the shubharthi has always been an introvert and prefer to be left alone? In such scenario he/she may not like to be in a group of people. So, it's better to leave him/her alone and let him/her mix up as and when he/she feels like.

b. Another reason can be because of the symptoms that he/she is experiencing he doesn't want to mix with people. Many a times hallucinations, excessive thoughts are very disturbing and hampers smooth communication. Here the shubharthi will prefer being alone.

c. At times discomfort caused by the side- effects of medication limits the Shubharthis social interaction. For example, side-effects like dryness of mouth or pacing up and down, restlessness makes it difficult for the Shubharthi to interact with anyone, as one cannot have proper conversation with these side effects.

d. Another factor is delusion that the shubharthi may be experiencing. If he/she feels that people are looking at me or against me, or plotting against me. In such scenario the shubharthi will be very scared and anxious to get out of the security of his/her room and avoid socializing.

e. Many a times in social gatherings people ask questions related to personal life like about occupation, marriage, future plans etc. Our shubharthis' may not have answers for these questions and feel intimidated. They feel sad and avoid social interactions.

f. Shubharthis have a tendency to avoid social gatherings, if earlier, in the acute phase of illness they have behaved in socially undesirable manner, have spoken in appropriately to others or have created a major scene. These memories can cause embarrassment and anxiety to them and they avoid further social gathering.

Friends there can be different reasons mentioned above right from their personality, symptoms, side effects, earlier behavior etc. which can cause shubharthi to avoid socialization. It is best as a caregiver to make note of the incidences in the shubharthi's life and his/her nature. It is better to discuss forthcoming social gatherings and ask him/her if he/she would like to participate. It is important to remember that social gatherings significant to you, may not be of importance to them. So avoid using force in such conditions. If the shubharthi is normally interacting with people but has suddenly withdrawn or stopped interacting thenit's better to have word with him/ her. Make a note of F-I-D and report to the treating psychiatrist, if there is increase in any parameter.

7. Shubharthi avoids guests at home:

Above mentioned reasons can also be applicable for this problem. Try to identify people with whom he/she comfortable and whom he/she is avoiding. It's better to tell the shubharthi beforehand if any guests are coming - who is coming, why, for how long they will be around. This will give shubharthis time to prepare themselves. They should be given a choice of if they would like to sit and chat with the guests or just say hello and go to his/her room. Shubharthi may opt not to interact at all, and it's fine. Precaution needs to be taken if the shubharthi has any negative feelings or delusion about the people coming. Don't expect the shubharthi to interact with them or don't force him/her to do so. Even in this scenario if the shubharthi was interacting earlier and has now stopped then start making note on F-I-D and then report to the doctor if there is increase in any of the parameters. Please avoid inviting guests if the shubharthi is experiencing active hallucinations or there is increase in any other symptom observed for a long time.

8. Shubharthi gets up late in the morning or sleeps throughout the day:

These problems are faced mainly by partially functioning or non-functioning people suffering from schizophrenia. Shubharthis who are not working or studying& are at home 24x7 are called non-functioning. They fail to follow particular routine when at home. They get up late, have food, sleep in the afternoon get up in the evening, have dinner, watch TV or read something and go off to sleep late. Again the same cycle follows. In this type of routine nothing active is done on the physical or mental level. So, they develop lethargy & tend to get up late. Important aspect here is that they have nothing to look forward to in the day. And this is the case for all the days of the year. There is no motivation to get up and do anything. Another problem is reaction of the caregivers. Caregivers many times react by saying "You don't have anything on your agenda so don't interfere in our routine". Such type of remarks can add to the problem.

Sedation can be side effect of medication, so it needs to be clarified with the doctor how much of sedation will the prescribed medicines cause.

Because of lack of any constructive day-to-day activity and taking medication for long lot of lethargy sets in. This lethargy can lead to more sleep.

An attempt can be made by the caregivers to motivate them to go for walk or walk for some time in the house itself. Suggesting to do yoga, going to the gym or doing errands to help the parents can be tried. It is necessary for the caregivers to understand that you cannot force any activity on them. That is their limitation and hence there is no point getting frustrated or angry over it.

For shubharthis who have definite routine and find it difficult to get up in the morning or those who feel sedated and drowsy even after getting up should discuss it with the doctor. Medication can be taken in the late evening to lessen the sedative effect experienced in the morning.

9. Shubharthi refuses to take bath:

Shubharthi's refusal to take bath is one of the symptoms of schizophrenia. This shows that he/she lacks the need to maintain hygiene. Other day to day activities like changing clothes, combing, brushing and eating can also get affected. There is a need to keep a watch on this. Trying to offer incentives like spending time with the shubharthi, getting what he/she likes can be given, if he/she takes bath can be attempted. Reporting this to the doctor after rating it on F-I-D for a week is essential. Also it is important to check if avoiding bath is related to any hallucination or delusion.

10. Shubharthi asks questions repetitively:

Asking same questions again and again can be one of the behaviors of the shubharthi mainly who are chronically ill. This can be very irritating to the caregivers. Shubharthi tends to ask questions repeatedly for different reason. They want interaction but have no range of topics to start conversation. Many a times shubharthi wants confirmation and assurance from the caregivers regarding any issue of their concern so they repeat questions. At times the shubharthi is so lost in his/her own thoughts that they forget the answers given by the caregivers or at times even forget that they have already asked the questions. Caregivers can write down the answer on the paper or board or in a note book and ask the Shubharthi to refer to it. If there is sudden increase in frequency and if there is intense emotional reaction from the Shubharthi if the answer is not given talk to his/ her doctor. Also try discussing it with the Shubharthi when he/she is in a receptive mood. At times shubharthis ask 'common sense' questions which we generally assume that they would know. For example, if you ask a shubharthi to make potato curry& give all the instructions but don't mention to add salt, he/she will ask if salt is to be added. Here we as lay people assume that while making curry salt is to be added & don't mention it. But that is not the case with shubharthis. They need proper and clear instructions.

11. Shubharthi cries easily or gets emotional and hypersensitive:

When there is increase in the frequency of crying on part of the shubharthi first try to find out the reason. There can be different reasons which can make shubharthi emotional depending on the condition and life stage of the shubharthi for example, if he/she is non-

functioning that can be the reason, if divorcee can be remembering the spouse & kids which can cause him/her to get emotional, failure in any form can induce crying, fights with near and dear ones can be troublesome etc.

If there is increase in all three parameters F-I-D please see the doctor immediately. Take help of the counselor as and when necessary. Observe the shubharthi and let him/her know that you are there to help. Don't force your help. That can irritate the shubharthi. Here you can say, *"I see that you are getting disturbed easily and staying to self. Is something bothering you? I am here if you wish to talk to me."* Don't, challenge his/her emotions or argue with the shubharthi saying it is foolish to cry for simple thing. Check if this behavior is observed with sadness and depressed mood throughout the day for a long time. Also keep a note of food intake, weight loss, expressed suicidal wish, feeling or expression of hopelessness and deteriorated social interaction.

12. Shubharthi lacks motivation and interest to do anything:

After positive symptoms like hallucinations and delusions are treated, shubharthi may take time to get adjusted to his/her normal routine. Lack of motivation and interest is seen in this stage or when the illness becomes chronic. Counseling the shubharthis and the family can be helpful. For shubharthis who are facing this problem for a long time, may find it very challenging to develop interest in anything. They can try and workout different options to motivate the shubharthi to do something e.g. include him/her in daily chores like cleaning the house, cooking, buying, organizing etc. Giving different alternatives can be tried. This can become difficult especially if the shubharthi lacks interest and motivation to try out new things. In such cases it is better to reinforce what they are already doing. See to it that they don't stop doing what they are already following or doing. Appreciate small efforts that they take. Making them feel wanted, feel important, is very essential.

13. Shubharthi indulges in frequent tea consumption or abuses tobacco or smokes:

Studies have shown that people suffering from schizophrenia have a tendency to frequently take tea or tobacco or both. It has been suggested that, this could be because it reduces their psychotic symptoms. Shubharthis need to be encouraged to use other alternatives like mint instead of tobacco. Discuss this with the doctor. But remember this habit can be very challenging to stop especially if the shubharthi lacks insight into the side effects of it.

14. Shubharthis have problems in attention and concentration:

Lack of attention and concentration is very commonly experienced by people suffering from schizophrenia. This is mainly because of the neuro-chemical imbalance that causes this illness. They may also find it difficult to do multitasking. Shubharthis should be

encouraged to do only one or two tasks at a time. Giving clear instructions is very helpful. Make instructions as simple as possible. Give reminders of next step or about their planning if you find them confused. Increase in F-I-D of lack of attention & concentration needs to be reported to the treating psychiatrist.

15. Getting restless or pacing up and down the room:

These are common side effects of anti-psychotics which are observed in the shubharthis. Involving them in some constructive activity may reduce restlessness and pacing to an extent. Developing shubharthis insight into this side effect is helpful. If it becomes very challenging and tiring report to the doctor.

Friends just now we saw possible challenges that we face in our day-to-day life while caring for a person suffering from schizophrenia. These challenges that we spoke about are commonly seen with the shubharthis. There can be case specific challenges which you can discuss with your counselor or the treating psychiatrist. You can start understanding the challenge by rating it on F-I-D that will give insight about that specific problem and encourage you to find solutions.

On the next page, try to check for yourself: do you have your own prejudices which you have to work on first?

Do I respond in this manner: Yes/No

Do I lose patience?

Do I feel nothing will change?

Do I feel my Shubharthi is doing this on purpose?

Do I feel the Shubharthi just wants to test me and my patience?

Do I feel I am unlucky and lonely?

Do I feel I am being punished for something I did?

YOUR PAGE Activity 4

Which of the following challenges are faced by my Shubharthi?
Just mention Yes or No in front of the activity mentioned below.

- Not ready to take medicines.
- Not ready to interact with guests.
- Doesn't like to come for social functions.
- Refuses to go to college/ job.
- Frequently gets angry.
- Drinking tea frequently.
- Smoking frequently.
- Asks same questions repeatedly.
- Lacks motivation to do any work.
- Likes to be left alone.
- Paces ups and down the room.
- Unable to pay attention and concentration.
- Closes windows and doors of the room.
- Refuses to take bath.
- Drinks water frequently.
- Cries easily or becomes hypersensitive.
- Getting up late in the morning.
- Sleeps a lot throughout the day.
- Uses same set of clothes.

- Any other observation

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YOUR PAGE Activity 5

Also make a note of how you respond to these observations. What is your reasoning for these behaviours observed in your Shubharthi? What can be the helpful way of understanding these behaviors with reference to your Shubharthi?

Read the textbox below before you start. It may help you see things in a different light.

Instead of saying
"*You are such a lazy fellow. You get up 11-12 in the noon, eat and sleep again. Why can't you help me do some work."*

You can say
"I can understand it is difficult to get up early when you don't have any work scheduled in the day. Will you like to please help me in my work so that we can spend some time together."

How do I actually respond?	**How could I think so that it will help me?**

Let us go further and look into certain basic principles of handling this challenge of caring for a person with schizophrenia.

Factors within the control of the caregivers and factors beyond the control of the caregivers :

Let us try to understand what are the "factors within the control of a caregiver" and "factors that are beyond the control of a caregiver". While taking care of the shubharthi one tends to feel burdened about many things. Many a times we as a caregiver want to control 'everything' around the life of the shubharthi. One feels responsible for all 'good' and 'bad' things happening around. This adds to the already existing burden. Let us try and make a list of things that are actually in our hands as a caregiver.

Factors within the control of the caregivers.

a) Taking care of the Shubharthi :

As a family member one feels responsible for other persons wellbeing. This responsibility increases when a family member suffers from schizophrenia. (or any other type of chronic mental illness). Taking care of the shubharthi will involve 3 steps.

Step I - Observation: As a family member one has to observe and note down the important changes in the shubharthi. These changes can be related tohis/her behavior, emotional reaction pattern, occurrence of hallucinations or expression of delusions etc. Keeping a separate diary of this helps while making notes or jotting down points. This note making also helps in understanding the shubharthi and his/her reaction pattern. These observations are to be noted down as objectively as possible without coloring it with the prejudices, biases, and judgments of the caregiver. Use of F-I-D is extremely helpful.

Step II – Reporting: This step includes reporting all the significant observations between the two follow-ups to the doctor. Again, as mentioned earlier the observations need to be rated on F-I-D and reported objectively. For example, if just two days before the follow-up the shubharthi gets angry for some reason how will the caregiver report it with prejudice or objectively? –

A biased, prejudiced reporting would be *"Doctor he gets angry a lot these days. He has extremely poor tolerance. His younger brother just said something and he reacted violently and abusively. We all were very scared. There is no point telling him anything. He is useless doesn't understand how much we care for him".*

An objective caregiver will say *"Since the last follow-up Mahesh is emotionally much stable. He just got angry once two days ago because he was upset about the way his younger brother spoke to him."*

IMPORTANT: Often the treating psychiatrist may also carry the same bias. So let us look into how reporting could or should be done. Is there a framing bias operating? If so, let us remove it at the outset. Use examples of statements that reflect a bias on part of both, professional as well as Shubhankar.

This feedback helps the doctor to understand shubharthis condition. If the observations suggest increase in F-I-D then the doctor can be contacted earlier also, even before the scheduled follow-up visit.

Step III - Implementation: This part of care involves following strictly whatever the treating doctor and/or the psychologists recommends: supervising medication, giving **appropriate emotional and behavioral reactions**, supporting the shubharthi, going for regular counseling, are all parts of this process.

Let us see in the textbox below how to deal with a situation in a way that is appropriate.
Eg. we do not want to treat the Shubharthi like a helpless person or a baby.
Let us see how you can be of help to your Shubharthi. Let us practice this ROLE PLAY.

Santosh: "Didi, baba has asked me to deposit this cheque in the bank. I am confused how to fill the details in this slip he gave. Will you please help me?"
Didi " Yes Santosh I will try to help you. Now on the slip what are the details that they want?"
Santosh: "they asked name and account number"
Didi: "yes and also the amount and date, correct?"
Santosh: "yes"
Didi " so now let us fill in the details, cheque is in whose name? from which bank and cheque number?
Santosh: "Cheque is in baba's name from ABCD bank, 5000 Rs is the amount and dated 5th June 2023, but where is the cheque number didi?"
Didi: "Santosh you have given all the details correctly, the cheque number mentioned down mostly on the left side of the cheque and is a 6 digits number"
Santosh: "Ok, didi. So on the slip payee name will be baba's name, I will write it. His account number he has written for me on the paper, I will copy that"
Didi: "Good going Santosh"
Santosh: "Now I will also have to write the amount in numbers and words, correct?"
Didi: "Correct, Santosh, see you know how to do it"
Santosh: "what else didi?"
Didi: "Now under cheque details column please write name of the bank, name of the branch, cheque number and amount."
Santosh: " ok didi, but why these details? And why to write them twice in two parts of the slip"
Didi: "These details help us to track the cheque which we have deposited. See we write this information on both the sides of the slip. One part will go with the cheque to the bank and other part will stay with you after they stamp it. That piece of paper will have all the details of the cheque deposited."
Santosh: " So baba will know that I have deposited the cheque."
Didi: "yes and also he can trace it till it gets deposited."
Santosh: "Oh understood. Now I will go to the bank and deposit it. But on which counter to deposit it didi?"
Didi: "even I am not sure as I have not gone to the bank in many months. Please ask the guard there. He will guide you."
Santosh: "I will try as you said."

b) Informing and discussing about shubharthi with other family members:

Most of the times it is observed in the family that there is one caregiver who takes the lead in the treatment process. We call this person a 'primary caregiver'. Shubharthi mostly has strong emotional bonding and trust with this person. This primary caregiver is totally involved in the treatment schedule, follow-ups, supervising day to day medication, observing the shubharthi etc. Other members in the family, though present, will be on the periphery. They may or may not be involved in the treatment process. How and when to inform and involve other family members about the shubharthi's illness is within the control of this primary caregiver. This can be done with the help of the doctor. Information given in an objective way is more effective rather than adding one's subjective evaluation. Here **words should be chosen with precaution**. The primary caregiver with the help of the doctor, can discuss with other family members what this illness does and what type of behavior is expected from the shubharthi. The family can come up with a proper action plan about how they can best interact with their Shubharthi, after discussing it with doctor or the counselor.

Read the text boxes on the next couple of pages carefully. Try out the role play to see how it helps to keep a positive mood in the family.

The same statements can be worded in a positive, healthy manner, and help maintain a healthy atmosphere and respect for our Shubharthi.

Maa: “ Vikram, where are you?”

Vikram: “Yes Maa, I am here, what happened?”

Maa: “ Me and Daddy want to talk to you something important.”

Vikram: “Yes maa, tell me what happened?”

Maa: “it’s about Varsha”

Vikram: “what about her?”

Maa: “the other day you were asking me why she is picking fights with you or me, correct?”

Vikram; “yes maa you agree na, she had become a fighter cock. Don’t know what is wrong with her. She doesn’t study and stares at the ceiling.”

Daddy: “yes that’s what we want to talk to you. Vikram we took her to a doctor this week. She said she cannot pay attention to what is taught in the college or while reading her texts. She doesn’t understand what is read. She forgets what is read. So we spoke to our Dr Rajat uncle. He asked us to meet a psychiatrist.”

Vikram: “Psychiatrist? She is not mad Daddy”

Daddy: “You are right Vikram; she is not mad. But there are some neuro chemical changes that are happening in her brain because of which she is unable to concentrate, or comprehend or memories. She gets frustrated easily and hence fights. Doctor Shastri the psychiatrist has given her some medication which will surely help her.”

Vikram: “that is good. But how will the medication help her?

Daddy: “the medication will work on the neurochemical imbalance that has happened in her brain. Once that happens, she will be able to think properly, be emotionaly stable and concentrate. That will help her, right?”

Vikram: “Yes Daddy, But now what should I do? What should I talk to her?”

Maa: “Just be around, don’t ask too many questions, if she wants to talk, talk for some time about neutral topics or topics of her interest. If you feel irritated or angry about something Varsha says or does, instead of reacting just come and discuss it with us”

Vikram: “I will. Thanks for telling me Maa-Daddy. I will try my best to be a good helpful elder brother. She will soon feel better”

A few examples are given below which shows positive and effective responses of the caregivers.

- Aakash came home from his office and told his wife that he will resign from his job as he was to be transferred to another branch. His wife Swapna initially grew anxious, but then collected herself and said "I know it is difficult for you to adjust to any change that comes your way. Is that making you anxious and stressed about the transfer as there will be new office and new people?" Aakash said "Yes how will I adjust?" Swapna "Hmm, I can understand. And the department? Will it be the same or different? Aakash "Same department but different branch".
  " In a way this is good so your job will be the same. You have some tea. We will discuss it later and see what can be done. I am with you in this process."

- Rakesh's mother found that he had not taken his medication last night and she is talking to him. "Rakesh, I just found out that you didn't take your dose last night, what happened?" "Mummy I don't like that medicine. It causes lots of constipation." "I know Rakesh you don't feel up to mark when you are constipated, but at the same time this medication is also very important to control your anxiety and fear. Isn't it?" "Yes, mummy it reduces my fear but this problem arises. I don't want to take it." "Rakesh we will definitely discuss this problem when we visit the doctor next time, but till let us see what additions you can do in your diet for dinner. We will add more of leafy vegetables and salads to our menu. That will help with reducing the constipation. What do you feel?" "I will try but stop the medicine if I feel constipated." "Agreed, let us also goa and discuss this with the doctor."

c) When and how to inform relatives, neighbours, friends and significant others:

In Indian scenario we all know that after the immediate family members, on social level we interact with neighbors, relatives, friends, colleagues etc. These also form a significant circle of interaction. Primary caregiver with the consensus of the shubharthi and other family members can decide when and whom to tell about the shubharthis condition. At times without the knowledge of the shubharthi, the caregivers using their judgment have to take the decision, to inform the significant others e.g. colleagues, friends. While selecting these people one can think how empathic they are with the shubharthi, what type of relationship, emotional bonding they share with the shubharthi, is that person non-judgmental and have unconditional acceptance of shubharthi needs to be taken into consideration. The family members have to give information, which is objective and precise. If all the family members deliver standard information, it avoids confusion and misunderstanding in the people concerned. Especially while informing to colleagues and friends, the caregivers can also give a guideline of what they need to observe& how they need to support the shubharthi if he/she gets disturbed.

Read the text box on the next page carefully. Sometimes it helps to choose a co-therapist from among family and close friends. This will help reduce pressure on the primary caregiver.

To decide on choosing a co-therapist following points need to be considered.

- Observe the shubharthi when he/she is with different people from the family, relatives, friends or neighbors. Understand that our shubharthi is less likely to have a wide range of people with whom he/she will be comfortable.
- After narrowing down on these few people, observe how these people interact with your shubharthi. What makes the shubharthi comfortable with them?
- These people are likely to have qualities like patiently listening, not labelling the shubharthi, accepting the shubharthi not questioning about the shubharthis achievements, not asking constant questions like when will you complete you education, when will you start earning, when will you get married etc.
- When you zero down on these selected few discuss with the shubharthi about taking help from them. If the shubharthi approves it becomes a open communication between all of you and the chances of the shubharthi developing any type of negative or suspicious thoughts are reduced. At times the Shubharthi may no be ready to take help from anyone, in such scenarios if its necessary the caregiver will have to use his/her judgment and take help without the knowledge of the shubharthi. It is important to note that the person selected must have genuine interest in the wellbeing of the shubharthi.
- If this person is your shubharthis college friend, you can take feedback from him/her about what challenges the shubharthi faces in college. If the shubharthi is not attending the college this friend can be help in completing notes and other asssignments. This friend can be a vey good emotional support if the shubharthi wants to attempt going to the college.
- If this person works with your shubharthi in his/her office then he/she can give you feedback about his day-to-day performance in the office or if there are any challenges or changes in the office. With the help of this friend, you can discuss and plan with the shubharthi different strategies that are necessary to face the upcoming challenges.
- If this person is a neighbor or a relative his/her help can be taken for socialization of the shubharthi. This person can also be trusted with the role of accompanying the shubharthi to the doctor for follow-up in absence of primary caregiver.
- All these well-wishers can be informed about the challenges faced by the shubharthi, symptoms and medication process the way it is discussed in the earlier section. (please refer to the dialogue between Vikram and his parents)

d) Supporting and helping the Shubharthi:

This is the main agenda of any caregiver. One needs to understand what support and help the shubharthi needs. That will depend on different aspects like functioning of the shubharthi. A fully functioning shubharthi may need less of help in day-to-day activities but need more of emotional support. A shubharthi who is low functioning will need guidance even in planning his/her day-to-day activities. Encouraging and reinforcing his/her attempts to do something constructive is necessary. The caregiver needs to be flexible in the day-to-day support & help given. It is also important to remember that the shubharthi should not become totally dependent on the caregiver. Making the shubharthi independent to take care of self should be the goal of any shubhankar.

e) Caregivers thinking and reactions:

We as human beings have access and control over our thinking and emotions. Caregivers thinking and reactions are under their control. If the caregiver's reactions are creating problem for the shubharthi they can be corrected with the help of the counselor. Our thinking causes our emotional reactions. A caregiver can work on his/her reaction pattern. A detail discussion to understand more about the thinking and emotional pattern of the caregivers will be dealt in next session.

Factors beyond the control of the caregivers: -

a] Shubharthi's reactions:

Caregiver loves the shubharthi and does whatever he/she can do for the shubharthi's well being. Many a times you get positive response from the shubharthi, but there are times when you don't get a desirable response from the shubharthi. These are the times when you tend to lose hope and come under the influence of extreme negative emotions. One needs to understand that the caregivers have no control over how the shubharthi reacts to the efforts taken by the caregivers. Shubharthis reaction can be the result of his/ her thinking, perception, part of illness or his/ her personality. Caregivers are not responsible for such reactions. Shubharthis may also lack consistency in their reactions. It's better to understand, their reactions to you& their behavior with the help of the counselor. This will give you clarity about what you as a caregiver can do and what is beyond your limit. Avoid taking control of shubharthis reactions caused by his/her illness.

b] Course of illness:

In spite of following all the recommendations given by the doctor for e.g. supervising and ensuring that the shubharthi is taking medication on time, reacting appropriately to the changes in shubharthis mood and behavior, there can still be a relapse. At times even the treating psychiatrist has no specific answer for such

relapse. In such conditions the caregivers get a common thought “I do everything possible for the shubharthi, but still, he/she is not getting well”. Here the caregivers need to understand that the course of illness is not under the caregiver’s control. What changes take place in the neurochemicals in the brain, caregivers have no control over it.

c] Reactions of the other family members:

The primary caregiver always feels responsible for the happenings in the family and its effect on the shubharthi. It is but natural to feel that all family members should be empathetic towards the shubharthi. One needs to remember that individual may differ in understanding of the same situation and condition. All the family members may not understand the shubharthi and the illness with same cognition and comprehension. Intensity of reactions may also differ. As a primary caregiver one can explain to the other family members what type of understanding and behavior is expected when there is a person suffering from schizophrenia in the family. It is very important to remember that one cannot have control over the thinking and behavior of other family members.

d] Reactions of the relatives, neighbors and other significant people:

Individuals differ in thinking and understanding. This depending on their overall comprehension and understanding. There may be some positive and negative reactions from this set of people. Whenever possible one can explain to them about the condition of the shubharthi and expected reaction patterns. But we as caregivers can never have control over their reactions.

e] Other life Stressors:

It is extremely difficult to predict which new challenges one has to face in life for example change in job, business failure, health related problems, marital discord, retirement, family members going abroad or start staying independently, death of loved one etc. As a caregiver we wish to protect our shubharthi from any such changes. But most important aspect that one needs to understand is that no one has control over the life changes. During such period of change one can be more supportive towards the shubharthi. We as caregivers need to remember that we cannot control the happenings around.

See end of the document…….*preparing Shubharthi for possible change.*

B] Calamity v/s Difficulty :

There are some people around us whom we see giving exaggerated reactions to changes in their life. Such people treat any change in life as calamity. Let us take an example – A man in his late twenties loses his hand in an accident. This is definitely an unfortunate thing to happen to anyone. The family will be devastated. They will experience a range of negative emotions. This will be the initial phase. The family has two choices – one is to continue to react to this with intense negative reactions and consider it as 'calamity' or look at it as a 'difficulty' and start looking out for alternatives to help the person affected. A person who continues to look it as a calamity will start feeling that it is impossible to survive in this situation. He will lose all hopes, break down and fail to look out for alternatives to help him. He will reach a "no way out" situation.

On the contrary if the family looks at this situation as a 'difficulty' they may have different thoughts like "this is really a very trying situation, but we are lucky that he was saved from the accident and is alive. We will try our best to help him in all possible ways. We will train him to do all the things with other hand and make him stronger. We will also look out for options of prosthetic arm. With medical science developed to a great extent, we will surely find good alternatives for him". This family will look out for all the possible actions within their reach.

When a person suffers from schizophrenia it's a major blow to the family members. They feel devastated and look at it as a calamity. The caregiver can ask self what if this near and dear one was totally dependent on the caregiver for all the physical needs? Wouldn't it be more challenging? What if the shubharthi was involved in drinking, gambling, drugs and other vices? Wouldn't it be challenging in a different way? Agreed it is a difficult situation to see your near and dear one; a grown-up suffering & not functioning. Yes, it is indeed a difficulty.

As a caregiver one can look back into your own reaction pattern and check when have you reacted to the situation as "calamity" and when have you treated it as a difficulty. This will give you insight into what was more burdening.

C] <u>Optimistic v/s Realistic -</u>

When people around us know 'about the problem that the family is facing one common suggestion or advice that we get is 'be positive', or "everything will be fine, don't worry" etc. We know in reality things are different. Deep down the heart we hope that one day everything will be fine. But things don't change the way we want them to change. It is good to say that things will change positively. One has to be optimistic in life. But being only optimistic does not help. Just sitting and hoping for miracle can at times make us 'inactive'. We may stop taking necessary steps to achieve our goals. Then how will our hope change into reality? Now let us look again take help of our friend who has lost his hand. The family hopes, wishes and is optimistic that some miracle will happen and he will

get his hand back. Here they are drifting from reality, from actual fact that he may never get his hand back. So what is the realistic alternative? He can start thinking of the option of artificial limb. It is a realistic thought and alternative that artificial limb will help him re-establish his life. This will guide the families' effort in a proper constructive way and towards a realistic goal.

With our shubharthis' having an idea of what their condition is and how much they can achieve after the episode of schizophrenia is very important. Resetting of goals as and when needed is a more realistic option. A shubharthi who is unable to complete his engineering degree in past 4/5 years needs to look at resetting his goals. He needs to discuss it with his doctor and counselor about how many more attempts he need to give with his age now around 24-25 years. Will he be able to get adjusted in the college with the younger crowd? Will the problems of attention and concentration allow him to study the way he used to before the onset of schizophrenia? If it is not possible to continue with engineering, what other courses can he opt for? Again, starting here with small term 2/3 months course will be a better option. So, looking and trying out more achievable goals is essential and more realistic.

Would like to share another example. A young girl in her 20's got leukemia. Her chemotherapy cycles were over and she was getting back to her daily routine. One day she with her parents came to the institute. Her parents in, her presence explained her condition to me and added "You now talk to her and convince her that she is 100% all right and can lead a normal life. Like other girls she can get married, have children, work and live happily. Just explain this to her that she is completely fine". After saying this they left the room. Before I could say anything, the girl said "actually I am not worried for myself, but for my parents. You have just heard what they think. I agree that today I am completely alright, free from any malignancy. But the fact remains that I may suffer a relapse at any point in life. I would love to get married and have children like other girls. But I will take all the decisions only after consulting my doctor. Today I would like to first concentrate on my career and think of other things later". Obviously, the girl in the picture is realistic then her parents who are optimistic and wish well for her. **Total acceptance of the facts comes when one is realistic.**

Read the text box on the next page carefully. It will help us all decide if we are being realistic.

How do I know I am being realistic?

I am being realistic as a caregiver if…

- I am taking proper medical help from the mental health professionals and following their guidance.
- I am not accusing the shubharthi of his condition. I don't blame him for his failures or lack of achievements.
- I am accepting the illness and understand the limitations caused by the illness.
- I share my duties with other caregivers and as and when needed take a break for myself.
- I am following my religious rituals and praying for the shubharthis wellbeing, but not forcing or pressurizing the shubharthi to follow the rituals.
- I feel saddened by the condition of my shubharthi, but I am also aware of the limitations this illness has caused.
- I don't engage in false promises given by other type of treatment schools and stop the present treatment that is helping him. I have accepted that this treatment will have its own side effects, which are manageable as compared to the symptoms experienced by the shubharthi.
- I accept that my shubharthi won't be able to complete his education and work like other friends of his. I will focus on making him independent so that he can take care of himself when alone. I will train him to do basic cooking, handle basic finances and take care of the basic household responsibilities.
- I know after this divorce my shubharthi is our responsibility. Sadly she was unable to have a healthy married life because of the limitations caused by schizophrenia. I will try my best to support her till my last breath.
- This illness is caused by the neurochemical changes occurring in the brain. The shubharthi is not responsible for it. At the same time, I may have erred as a parent but my faulty parenting has not caused this illness. Now it is better to focus on treatment and help the shubharthi deal with this challenge.

Section – III

Coping with the emotional challenges faced by the Shubhankars:

(In this session we will be talking about thoughts and emotions of a caregiver.)

Caring for a person suffering from schizophrenia can be emotionally exhausting. We caregivers are with our shubharthis 24x7, 365 days a year. This proximity itself can be very demanding. Though the caregivers feel tired, they never stop caring. This is long-term, never ending commitment. There are times when the caregivers feel tired, demotivated, frustrated, hopeless, depressed, anxious, angry, helpless, jealous and experience a range of other negative emotions. Today let us see how we can ease out few emotions, understand the key thought process which can give rise to different emotions.

This emotional exhaustion of the caregiver is called 'burn out' in scientific terms. Let us use a more common word emotional fatigue. There are different reasons by which the caregiver experiences emotional fatigue. It can be because of the chronicity of the illness which make them feel exhausted of unending caregiving. As years pass by the age of the caregivers increases and their overall strength reduces. This is a type of continuous and unending parenting which the caregivers are forced to take up. When the shubharthi shows partial improvement and become treatment resistant the caregivers experience high amount of emotional fatigue.

What can be done to reduce this emotional fatigue? We all know that the stress or "illness of the shubharthi, our dear one" is always going to be around. We cannot change that factor. Then what is it that we can work on to reduce our fatigue?

The key to this is our outlook, how we look at the situation, what we think about our shubharthi, how much we accept the shubharthi with his/her illness will reduce our fatigue. It is not going to change the reality that our dear one is suffering from schizophrenia, he/she has limitations because of this illness, may not have a good career like others, may not have a normal married life, he/she will not add to the finances of the family but you will have to spend on him/her from your own pocket, your health and energies will fail with growing age, you will constantly worry about what will happen to him/her after you are gone, who will care for the shubharthis all these thoughts are bothering you intensely. You lose your sleep over it. With this constant stress, even you have developed different physical problems, you cannot take simple pleasures in life neither can you happily enjoy other relationships.

Friends there is no magic wand which will take away all these problems. Yes, but we together can definitely develop a healthy mindset in the given scenario and learn to live our life with less emotional fatigue and exhaustion.

Shubharthis need support when they grow more disturbed.

Our shubharthis can get disturbed for different reasons. At times it can be because of the hallucinations and delusions they experience or their inability to cope with the challenges they face in their life. In such scenarios the shubhankars needs to keep their patience and help the shubharthi. This needs lot of emotional energy and the shubhankars feel drained out. They may experience physical symptoms like headache, acidity, palpitations and so on. If the shubhankars are unable to regulate their emotions they tend to express it harshly in form of screaming, calling names, labelling, excessive uncontrolled crying or in extreme cases even harming self or the shubharthi. This type of incidences at home causes a lot of injury to the shubharthi and can trigger a major relapse.

Shubhankars too need support. They can get burnt out and exhausted.

Now the Shubhankars feel guilty and frustrated and don't find a way out. This is a classic example of 'burnout' or 'emotional exhaustion'. Here the shubhankars needs to learn to regulate different negative emotions like anger, guilt, frustration, over protection, depression etc. This module will help you to understand the thought patterns causing these emotions and strategies to cope with it.

Situations such as these, with the Shubhankar close to Burnout, can become a high risk point for **high expressed emotion (EE)** which may once again spiral into another relapse.

There is material in Manuals 2 and 4 which will help us understand this concept of Expressed Emotion and its importance in maintaining good health in the Shubharthi and Shubhankar. A Shubhankar needs to balance between anger and hostility and overprotection and this itself is very stressful.

IMPORTANT :

YOUR PAGE

Are we creating overdependence on ourselves? This would lead to our own detriment

and lead to disadvantage to the Shubharthi as well.

Let us complete this **self assessment checklist.**

Given below is list of some conditions you may experience/feel as a caregiver. Please rate it on the scale of '0' to '10' where '0' stands for never experienced/felt and '10' stands for always experienced/ felt.

1. I feel angry at the sight of my shubharthi.
2. I feel like running away from all my responsibilities.
3. I don't feel like getting up in the morning.
4. I wish that the shubharthi is no more.
5. I have committed some sin because of which I am suffering.
6. What will happen to my shubharthi after I die?
7. Who will take care of my shubharthi after my death?
8. No one cares for the shubharthi the way I do.
9. How can I enjoy anything when my shubharthi is suffering?
10. What is the use of all this treatment? My shubharthi has not come back to normal.
11. I experience some or the other physical symptoms like headache, palpitations, breathlessness, acidity, constipation, diarrhoea, sleep disturbance, chest pain etc.
12. I lose my temper easily.

Understanding the concept of empathy.

At IPH, we begin this section with a set of role plays which you will find below.

They are pretty self explanatory, but just to help us along, here is a short role play which reflects a dialogue between two friends and lets us see how empathy can be demonstrated.

Please go through it. When conducting your own trainings later, you can decide whether you want to use it, or skip it.

Let us look at the dialogue between the two friends Mugdha and Vira. Try to understand how Vira is responding to what Mugdha is saying. Vira is meeting Mugdha after a major attack of Hepatitis B. She was admitted to the hospital for nearly 10 days and is now back home.

Vira: Hi Mugdha, how are you feeling now?

Mugdha: I am better.

Vira: You must be feeling very weak?

Mugdha: yes I am.

Vira: I can understand. this must be really very difficult period for you.

Mugdha: yes Vira it was very difficult.

Vira: You must have worried a lot about Parth and Meeta as they are very young.

Mugdha: Yes Vira, they were missing me a lot and trying to help their father. Mahesh had to manage everything.

Vira: You must have been in two minds. But at the same time, it was also important for you to be in the hospital for good care, treatment and recovery. You must have felt like managing from home. But you will agree we can't take proper care of our health when we have other responsibilities.

Mugdha: yes Vira so only I decided to get admitted.

Vira: Now that you are home you can supervise the household chores, but please don't work yourself. Also I am back from my native place so I will also try to be of help to you. Now you rest. I will come back tomorrow.

In this scenario we can see that Vira is supporting Mugdha, but how? She is trying to understand and reflect on the possible emotions and thoughts that she can experience in the given scenario. She trying to verbalise those thoughts and emotions. This attempt shows that Vira is actually understanding what Mugdha went through. Mugdha feels understood and supported.

Now let us have a look at four sets of dialogues between a caregiver and the counsellor. We will try to find out how different these dialogues are which is the most effective and healthy one.

Here are the facilitators can role play this as 4 different scenarios or can say the lines of the caregiver with necessary effect. This will depend on availability of facilitators and

their skills. Start by narrating the case history given below. Here option of giving written scripts one by one to the group can also be considered.

Mr.Raghunath is father of 35 years old Girish who is suffering from schizophrenia since past 15-16 yrs. He is partially functioning shubharthi and is at home most of the times. He has recently started going to a rehab centre thrice a week. Girish stays with his father Raghunath and mother Suneeta. He is well maintained on medication. Raghunath has come for the follow-up with the psychiatrist and the psychiatrist has asked him to meet the counsellor.

The participants are instructed to observe the caregiver and make a note of his body language, eye contact, tone, etc. This will be discussed after every scenario.

(Here I am taking character of Mr.Raghunath. If the facilitator is female, character of Suneeta can be played. Gender of the counsellor can again depend on the availability of the facilitator)

Scene - I

Mr.Raghunath enters the counsellor's cabin. She greets him with a smile. He gives her a disinterested blank look and occupies the chair near the table.

Counselor : (She is going through the case papers and starts talking to him.) Hello Mr.Raghunath, you are Girish's father.

Mr.Raghunath : Yes.

Counselor : How can I help you?

Mr.Raghunath : I do not know Doctor asked me to meet you.

(He is disinterested and is not maintaining proper eye to eyecontact)

Counselor: Ok tell me how is Girish? What does he do?

Mr.Raghunath : He is fine, taking medicines, now going to Tridal the rehab centre thrice a week. (Looks at the counsellor. Tone is dry and monotonous).

Counselor: Nice to know that he is going to Tridal. We should see that he starts going every day of the week to Tridal. What do you feel?

Mr.Raghunath : Yes. Anything else? Can I leave?

(And he leaves the room)

Facilitators ask the participants about their observations and they come up with the following points. The caregiver appeared -

- Disinterested.
- Emotionally very dry.
- Lacked necessary eye-to-eye contact.
- Tone was monotone like a robot.
- He met the counsellor just to fulfil the doctor's suggestion. He overall lacked any interest in the process of treatment.

Now let us move on to next scenario.

Scene II

Girish's father storms in the room.

Mr.Raghunath : (Talks in a loud and commanding tone. He looks straight at the counselor). Are you the counselor? Doctor asked me to meet you. I am Girish's father.

Counselor : Hello, Yes I am the counsellor, how can I help you.

Mr.Raghunath : I do not know how you can help me.

Counselor: Tell me how is Girish?

Mr.Raghunath : Oh, that good for nothing fellow is fine, what is wrong with him. He eats, drinks, sleep. All his needs are fulfilled at the age of 35 without doing anything. He is happy. He can drive us crazy.

Counselor : Is he coming to Tridal, our rehab centre?

Mr.Raghunath : Yes. I don't know how it will help him to develop his career but he comes thrice a week. I hope he come daily, at least we will be at peace for 4/5 hours without him daily. Anything else? Can I leave? And he leaves.

Now how was this caregiver -

- He appeared arrogant, dominating.
- Was judgemental, labelling, and sarcastic.
- No acceptance of his son's illness or limitations.
- Antagonizing.
- Staring eye contact.

Scene III

(The caregiver comes in with a very serious face, heavy footsteps, sits in front of the counsellor with a very disheartened look and with a very anxious tone starts talking.)

Mr.Raghunath : Are you the counsellor? I am Girish's father, Raghunath. Doctor asked me to meet you. Is anything wrong with Girish? (He is very anxious while talking)

Counselor: No Mr.Raghunath nothing is wrong with Girish. This is a routine process. You tell me how is he? Does he come to Tridal now?

Mr.Raghunath : Oh. Nothing is wrong with him then it's okay. (Eyes down and talks as if he is talking to self). Yes, he comes to Tridal thrice a week. I don't know when he will get a job and start earning. He is 35 now. My boy could not even complete his engineering. He was very intelligent and promising. See what has happened to him. I hope he is cured fast.

Counselor: Yes. Mr.Raghunath even I feel that he should become independent. But let us now have a small goal of increasing his days at Tridal. Our target should be that he comes daily to Tridal. Also, I would like to see him take up some household responsibilities. What do you feel?

Mr.Raghunath : Yes he should first increase his days and help us at home. I will see what can be done. Can I leave now?

Now how was this caregiver?

- Anxious, extremely serious, negative.
- Maintained eye contact, inconsistently.
- Tonal quality fluctuated at times even appeared to be talking to self.
- Was talking as if there is no hope left.
- Was judgemental.
- Felt responsible for everything that his son does.

Scene IV

This caregiver enters the room with a smile, greets the counsellor and sits.

Mr.Raghunath : Hello, I am Mr.Raghunath. Doctor asked me to meet you. My son Girish is under his treatment.

Counsellor : Nice to see you Mr.Raghunath. How is Girish doing?

Mr.Raghunath : Yeah, he is fine. He has started coming to Tridal our rehab centre thrice a week. He feels fresh when he comes here. Though at times he is reluctant to come. We are happy that after so many years of gap he has at least started coming here. You know madam actually he was a very bright student and we believed he had a bright future (He says, this with a sadness in his tone). But now that he has started coming

here, is ready to help us in household tasks, is in itself very assuring. He now watches TV news, reads paper and discusses the happenings with me. So, I am hopeful, one day he will take care of himself.

Counsellor: Yes, surely. We will work towards making him as independent as he can. Even at Tridal he is taking initiative in learning new things. That is a good sign. He is becoming confident in the skills that he has acquired. We are happy with his progress. Now we all will motivate him to come daily to Tridal. What do you feel?

Mr.Raghunath : Thanks for your feedback madam. Yes, we will work together so that he starts coming daily. It was nice meeting you. Can I take your leave now madam?

Now let us try to list the characteristics of this caregiver. How was he?

a) He was positive, assuring.
b) Interested in the well-being of his son.
c) Was realistic
d) Tonal quality was soft.
e) Maintained eye to eye contact.
f) Was non-judgmental
g) Had good acceptance of reality.
h) He unconditionally accepted the shubharthi and loved and cared for him.
i) There was no blaming or labelling.
j) He was proactive.

We have seen 4 caregivers and listed the observations about them. Now let us name their patterns of communication.

1st Caregiver - Apathy

2nd Caregiver- Antipathy

3rd Caregiver- Sympathy

4th Caregiver- Empathy

Which reaction pattern was healthier and more effective?

The pattern of empathy was more effective. Because when the caregiver is on empathy track, he/she accepts the shubharthis illness and the limitation set by the illness unconditionally. This caregiver is concerned about the shubharthi but not overly burdened or emotionally fatigued.

This caregiver has realistic expectations from the shubharthi based on his present condition. This caregiver can have objective goals for the shubharthi. He can motivate the shubharthi without getting judgemental, without blaming and labelling the shubharthi.

This caregiver will have a healthy relationship with his shubharthi.

Similarly, pros and cons of other three styles should be discussed with help of following points.

		Apathy	**Antipathy**	**Sympathy**	**Empathy**
a	Acceptance of illness	x	x	No or present to some extent	Present
b	Realistic expectations	x	x	x	Present
c	Dominant emotions	Blank or Anger	Anger	Anxiety/Depression/ Fear/guilt	Concern
d	Emotional burden experienced	High	Very High	Very High	Manageable to less burden
e	Emotional fatigue	High	Very High	Very High	Manageable to less fatigue
f	Ability to enjoy other aspects of life	Absent	Absent	Absent	Present
g	Setting objective goal	Absent	Absent	Absent	Present
h	Interest in well-being of shubharthi	Absent	Absent	Fluctuates with emotional ups & downs	Constant
i	Relationship with shubharthi	Awkward	Emotional distance	Dependence on each other	Healthy
j	Emotionality of caregiver	Dry	Anti /injurious	Overwhelming	Balanced
k	Being judgemental	May or may not	Very judgemental	Very judgemental	Non-judgemental

Friends we have seen these four different styles of the caregiver. It is important to understand that we all react in these styles sometime or the other. It is observed that caregivers have a particular dominant style of reacting. It is important that each caregiver identify his/her dominant style of reaction. As seen in our presentation most effective communication style is when you are on the Empathy track. So a caregiver who wants to learn the effective style should focus on being on empathy track most of the time. This will not happen overnight but will need conscious efforts. This in itself is a learning process.

REBT model of understanding extreme emotional disturbance of the Caregiver.
REBT is a very helpful and good framework for Shubhankars. Refer them to a training process available easily. At the end of the Manual we have listed some references for REBT, simple books, websites, links, etc.

Further, let us find why we have different styles of reacting. The fathers' in this presentation had same problem their son Girish was suffering from schizophrenia, was unable to complete his education, was non-functioning at the age of 35. Though the fathers were facing same problem, their reactions were different. It will be interesting to find out why they reacted in different ways.

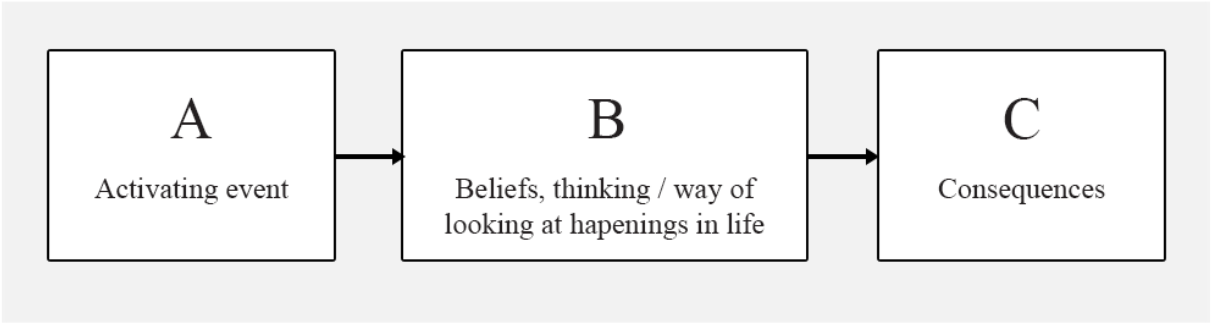
This difference will be explained with the help of a simple equation. We commonly say that anything happening in and around life causes reactions. For example

A ⟶ C	
Activating event.	Consequences
Girish suffering from schizophrenia.	Different reactions by father

We always claim that event causes its consequences i.e. A (Activating event) causes C (Consequences). If this equation stands true then let us examine another incidents. A boy commits suicide after he fails to clear his 12th standard exam.

Activating event (A) = failure in exam
Consequence(C) = suicide

If 'A' causes 'C' then all the children who fail in their 12thstandard exam will commit suicide. But this is not seen on reality. Each and every student who fails his 12th does not commit suicide because every student who has failed thinks about the failure in different ways. So the consequences will differ. Which means equation ‘A’ causes ‘C’ has to be re-examined.



Now according to this equation when an event occurs, we human beings think about it in a particular way, which will decide the consequences. [Here the facilitator can give different examples from day-to-day life.] Most important aspect of this equation that one needs to understand is events by themselves do not cause consequences, our thinking, outlook towards that event will decide what the consequences will be.

Consequences are in the form of different range of emotions and behaviour. Emotions can be positive like happiness, satisfaction, love etc. or negative like anger, depression, sadness, hatred, irritation, guilt, anxiety etc.

Now as a caregiver we have experienced a range of emotions mentioned above or there can be many more. At times these emotions make it difficult for us to relate to our relationships, at times they affect our physical health by causing illnesses like BP, diabetics, heart problems etc.

It is human to get preoccupied with thought about a person in whom one is involved emotionally. As a caregiver we think a lot about our shubharthi his/her illness, future security etc. These thoughts may be about how my “shubharthi was and he/she is now.” Thoughts can be about shubharthis improvement. These thoughts help us to work towards a constructive goal.

However these thoughts take a different turn when they pressurize us with different forms of ‘must’ and ‘shoulds’. They make us very obstinate and rigid. We start making irrational demands either from self (as a caregiver), or from the shubharthi or from the doctors or from other significant people. It is important to understand these 'must' and 'shoulds' and how they affect our emotional life. These 'musts' and 'shoulds' give rise to very intense emotional reactions and destructive behaviour. Let us make a list of these 'musts' and 'shoulds' of the caregivers and learn to replace them with more realistic and rational thoughts.

Identifying core unhealthy beliefs troubling the caregivers and replacing them with healthy rational beliefs.

Let us examine some common 'shoulds’ and 'musts' which caregivers have.

1. **Only 'I' can care for the shubharthi. No one else in this world can care for the shubharthi the way I do. Who else will care for the shubharthi the way I do?**

   These are different colours of the demand that a caregiver has from self. When a caregiver has this mind set it becomes extremely difficult for him/her to trust anyone and involve anyone in the process of caregiving. Many a times it happens that the caregiver is unable to delegate responsibilities to other members of the family. As a result they land up doing everything on their own. As years pass by no one else in the family is involved in the treatment process of the shubharthi and this primary caregiver gradually ages and starts becoming weak. The shubharthi is also totally dependent on this primary caregiver. Gradually the relationship becomes

burdening to the caregivers and effects his/her emotional and physical health to a great extent.

This type of caregivers need to tell themselves that "*all the members in the family have basic concern for the shubharthi. This concern can be different in intensity and can be expressed in their own ways. Even they can care for the shubharthi, look into the treatment process, follow-up with the doctorand supervise medication in their own ways. There is no point in demanding same amount of care and involvement as the primary caregiver. Most important is that medication is supervised and regular follow-ups are maintained. "*

2. **Caregivers demand from self that "I must take care of the Shubharthi till my last breath."**

This thought is commonly seen in on any caregivers. It is true that in the initial stages of the illness the shubharthi needs more attention. But as the illness settles, shubharthi develops insight into the problems and challenges. This is the time when focus should be on making the shubharthi independent. This independence can be related to day-to-day activities, doing basic bank work, dealing with minor financial responsibilities, learning household chores, taking responsibility of the follow-up with the doctor and medication etc.

Again this 'being independent' can depend on the overall functioning of the shubharthi. If a shubharthi is fully functioning, that is, having proper occupation, is taking responsibility of the family, then this demand from the caregiver is rarely seen. But when the shubharthi is low functioning and totally dependent on the family then the caregiver tends to feel totally responsible for his/her wellbeing. This attitude makes the shubharthi all the more dependent on the caregiver. This strengthens the belief that "I have to take care of the shubharthi till my last breath.'

In this case the healthy thought will be *"I will care for the shubharthi as much as I can. The shubharthi needs to know basic life skills for his/her survival and hence will work with the shubharthi to develop these skills."* This line of thinking will give a direction to the caregiver on setting different goals and working on it. Once the shubharthi starts taking responsibility the caregiver can trust him/her and anxiety of managing shubharthi can be reduced significantly.

3. **Shubharthi should be taken care of after my death, only I can ensure that. (In the same way that I do now).**

This is another very common demand that the caregivers have. It is but natural to feel that our shubharthi should live a descent life after the death of the caregivers. This worry causes lots of emotional ups and downs to the caregivers. Many times, they feel at loss because they don't know what will exactly happen after

their death. It is important to understand that is they can't have total control over happenings in shubharthis life during their life time or after death.

The most effective thought in such scenario is *'I as a caregiver make some arrangements so that my shubharthi will leave a decent life after my death. '*These arrangements will include making shubharthi independent in day-to-day functioning, making financial arrangements to support the shubharthi afterwards, involving other family members in this process of caring, forming a family trust for the benefit of the shubharthi with the help of significant others (will be discussed in detail later). This will definitely reduce the present anxiety of the caregiver.

4. **My only goal in life is taking care of the Shubharthi.**

On the face value, this statement sounds very noble and great. It gives a feeling of having a right direction, finding a mission in life. But is it helpful in long run? This needs to be examined. A person with this strong belief is dedicated 24x7 to the shubharthi. He/she tends to forget that there are other roles and responsibilities. The caregiver if working will have occupational goals, have other relationships to take care of, have other duties to look after. When they pay total attention only to the shubharthi, other relationships suffer. They don't have any energy left for other roles and responsibilities. This takes a toll on their emotional and physical health to a great extent. They even forget their responsibility towards their own self.

Coping and effective thought line up would be *"taking care of shubharthi is one of the most important responsibilities in life. I will do whatever I can and also as asked by the mental health professional to do. I will take help of the mental health professional as and when needed. I will also participate and enjoy my other relationships and also look after my own interest. I will gain energy from things I like to do so that I will be well equipped to take care of the shubharthi.*" These thoughts would help the caregiver plan his/her life in a much better way and without added guilt.

5. **"I cannot enjoy anything in life when my near and dear one is suffering from this grave illness."**

This core belief is observed in some caregivers mainly caring for partially functioning or low functioning shubharthis. They feel guilty to enjoy anything in life. It is very much understandable that one cannot enjoy life to its fullest when a near and dear one is suffering from schizophrenia or any other chronic mental or physical illness. This thought gives rise to further guilt and depression if behaved opposite or experienced happiness in some way or other. Even some nasty people blame the caregivers for enjoying when the shubharthi is suffering. At times even the shubharthis blame the caregivers for enjoying a movie or going on a trip. This tends to dampen the spirit of the caregivers and they stop enjoying anything. Ignoring the

emotional needs of self can cause lots of negative effects on the emotional health of the caregivers. They definitely have to prioritise their happiness once in a while. They need to understand that taking care of the shubharthi needs lots of emotional energy. The reserves of human emotional energy are limited and need to be refilled. These can be done by engaging in the positive activities that gives pleasure and happiness. This can be done by developing hobbies like music, painting, crafts, cooking, taking short trips, meeting people that make you happy, reading, yoga, meditation, taking up spiritual endeavours, gardening, having a pet etc. There can be learning new skills, languages or anything else. Dedicating specific time in the week for self is extremely essential. Caregiver needs to tell self. "*I am aware that I have to care for the shubharthi. I also need to look after my interest and do the things that I enjoy. If I have to recharge my batteries, I need to engage in different activities which will make me happy. I will generate positive energy from this happiness and take care of the shubharthi in a much better way without emotional and physical fatigue. (As a human being) I have the right to be happy."*

6. **"My Shubharthi should always take medication, properly, do all the work told to him/her, always be a responsible patient and follow my instructions. (In spite of the symptoms)"**

It is a logical thought that if the illness needs medication to be treated then medicine has to be taken. We have seen that this itself can be a challenge. Many shubharthis don't feel that there is any need for medication. They lack insight into their illness. This can be because their touch with reality is lost or is questionable to a very great extent. When the caregivers continue with this demand that the shubharthi should take the medication by hook or crook in spite of the stage of their illness, in spite of their symptoms there arises a major conflict. We have commonly heard the caregivers reporting major arguments fights over this issue. This issue can be further extended to how the shubharthi behaves, whether he/she does or follows whatever is told by the caregiver perfectly. Caregivers with a thought of **"I know what is best for you"** want to completely take charge of the shubharthis life. This appears threatening to the shubharthi and conflict arises. With rise in conflict the trust between the two weakens to a very great extent.

So now what is the helpful thought in the given scenario? We agree that taking medication is essential. Being functional and learning to be independent is also important. Please have a look at following thoughts -

- *"It will be really beneficial if he takes the medication on time. If not then I will have to work with the doctor to develop strategies to give him medication."*

- *"It is essential that he takes charge of different responsibilities in the house. He is not used to working in the house or doing things independently. He can*

start by doing simple tasks. Let me start by giving him options of 2/3 activities."

This set of thoughts gives direction to the caregiver what he/she can do. This in itself helps in reducing the stress of the caregiver. Also here the caregiver can keep a watch on the shubharthi's course of illness and check if he/she is in active phase of illness. If so, the caregiver can take steps accordingly.

7. **"The shubharthi is a lazy bones. He/she doesn't want to do any work just to trouble me."**

Some caregivers very strongly believe in this thought. Their caregiving is dominant by other related thoughts like the shubharthi is useless, good for nothing, worthless, a pain in my life, a major failure of my life, so on and so forth. When a person is full of such thoughts just the sight of shubharthi sitting ideal can cause intense anger and irritation. Yes, it is indeed painful to see our loved one, who is an adult, to be non-functioning. But attributing his being non-functional to he/she doing it deliberately causes more pain. It is essential to examine this belief. A healthier thought should be "*it is very painful to see my son unable to do any job. Yes, this illness has really taken toll on his functioning. He tried doing jobs but was unable to continue. Even he must be feeling very bad about it. At least he should learn certain skills which will help him stay independently when we are not around."*

You will agree that these thoughts will not change the reality but will definitely reduce the stress of the caregiver. The blame game and conflicts arising out of it will stop and it will give a direction to the caregiver to work on.

We have seen few 'musts' and 'shoulds' of the caregiver which can cause tremendous amount of stress to the caregiver. There can be many more depending on case to case. This 'musts' and 'shoulds' can be related to the socialization of the shubharthi, behaviour, emotional expression, his/her delusions, or any other aspect of the shubharthi as a person or his/her illness.

Healthy acceptance.

While examining the above 'shoulds' and 'musts' we have come across some common pointers for the caregivers to develop healthy thoughts.
They are as follows:

1. The caregivers thought need to take him/her towards a constructive goal.
2. The caregivers thought needs to be based on facts and realities
3. A healthy thought of the caregiver will always protect him/her from any type of intense emotional stress or turmoil.

4. When a caregiver has a healthy thought, he/she will not blame anyone –either self, shubharthi, other family members or fate for the happening in life.
5. Caregivers helpful thought will always direct him/her towards problem solving and finding constructive solutions.
6. A caregiver's healthy thought will help him/her to preserve all the emotional bonding with significant other relationships.
7. A healthy thought will help the caregiver stay away from intense negative emotions like anger, guilt, depression, anxiety, hatred etc.
8. A caregiver with healthy realistic thinking pattern will accept the shubharthi, his/her illness and the limitations caused by the illness without any conditions (unconditional acceptance).
9. A caregiver with realistic set of thinking will care for physical and emotional health of self.
10. A caregiver with healthy, helpful pattern of thinking will not terribalize the situation and gradually learn to regularise his/her emotions with experience.
11. A caregiver with the realistic bend of thinking will be clear that the shubharthis behaviour is a result of the illness (for e.g. not taking medication, not getting up in the morning, not socializing etc.) is the problem or challenge caused by the illness. He will not consider shubharthi in totality as a problem. He will not blame the shubharthi as a person.
12. This caregiver with healthy, helpful and realistic set of thinking will be well aware that 'ideal' or 'perfect' caregiver is a myth and similarly 'ideal' or 'perfect' shubharthi is also a myth. This caregiver will accept that caregiving is a learning process. Each and every experience will come with its teachings and 'I' as a caregiver needs to be open to these learnings.

(This session is based on Rational Emotive Behaviour Therapy by Dr. Albert Ellis. Facilitators are requested to read more on rational thinking and REBT for developing further knowledge).

Section IV

A - Communication

We relate to other living beings in this world by communicating with them. We share our thoughts, emotions with other human beings mainly because we feel the emotional need to share it with others.

With our shubharthis we have observed that many a times they talk less or even if they talk the content of their communication is limited. Caregivers and mental health

professionals have commonly observed that the shubharthis hardly talk about their inner feeling. There are times when they share their thoughts which troubled them the most which are mostly related to their hallucinations and delusions. As we know that schizophrenia is an illness of thinking and emotions. We all are aware by now that though they have excessive thoughts, the quality of their thoughts is very poor. They get repetitive thoughts for a long time which result in nothing worthwhile. At times they feel very tired and fatigued by this excessive thinking. They don't have much to share about happenings in their life especially if they are low-functioning. Communicating with the shubharthi can become very challenging.

As seen in earlier section as caregivers we need to develop the skill of empathic communication. Caregivers at times communicate with lot of emotions which can be overwhelming to the shubharthi. Sometimes caregivers become very sarcastic. Shubharthis feel the hurt but are unable to express and then keep thinking about such events repetitively.

Avoiding antipathy, sympathy or apathy in communication and being more empathetic is extremely essential for effective communication. Tonal quality pitch, eye-to-eye contact, speed of communication all are very important and significant while communicating with the shubharthi.

Given below are certain guidelines to communicate effectively with the shubharthi.

- Maintain proper eye-to-eye contact while communicating.
- Tone of the communication should be soft, pitch low and speed normal.
- Communicate using small and simple sentences.
- Give simple instructions not more than one or two at a time.
- Avoid communicating when you are emotionally disturbed or upset.
- Don't be sarcastic in your communication.
- Don't use 'blame' or 'swear' words while talking to shubharthi like "you are doing it purposely" or "it's because of you that I am in such a pain."
- Questions asked while communicating to the shubharthi should be simple, asked softly, in low pitch and normal speed. Questions should not sound like interrogation.
- Giving orders to the shubharthi should be avoided. Instead of saying "Do this" you can say "Will you please do this for me?" or "Will you please help me in doing this?"
- Don't challenge the delusions, hallucinations or emotions resulting out of it. Say "You must be feeling stressed when you hear those voices."
- When you are confused about what shubharthi is saying clear your doubt by saying "Will you please explain again/say again I did not follow what you want to say."
- Our shubharthis need proper, concrete instructions when you are asking them to do anything. It can be any household responsibility or going out to run errands. Especially while going out explain each task and sequence of task in simple words. Don't bombard the shubharthiwith instructions. You can give written instructions or ask the shubharthi to write down the instructions.

- If the shubharthi is disturb don't ask too many questions. Give him/herwater, pat on the shoulder and say "I am here if you want to come and talk anything. I would like to be of help to you."
- Shouting and screaming at the shubharthi when he/she does something wrong can be counterproductive. When you calm down explain in simple words what you expect from him/her. Avoid blaming and labelling as mentioned earlier.
- Say ‘sorry’ whenever you hurt him/her. It matters a lot.

Section IV

(B) Socialization.

Socializing is one of the important functions of the human beings. We all know that human beings are called 'social animal.' When human beings socialize, they develop a relationship with other human beings. This relationship can be temporary like talking to a shopkeeper, fruit seller, etc. or it can be an established one like talking to the family member or a relative or a friend. We all know that our shubharthi is not interested in interacting with others. They are more comfortable sitting in a corner and engrossed in thoughts. On the other hand, the caregivers want that the shubharthi mixes up with other people, talk to the family members or get involved in some social activities. Shubharthis are reluctant in doing any of these activities. So how to motivate the shubharthi to socialize.

First as a caregiver ask yourself why do you feel that the shubharthi should socialize? Whenever I ask this question to the caregivers, few of the answers that I get are as follows: -

- Shubharthi will feel good.
- It is expected to talk to other people.
- He/she will open up and feel free.
- If you are staying in a society, it is better to attend social functions and be a part of the group.
- How will others react if he/she doesn’t come for the function?
- Others ask us hundred questions when the shubharthi avoids the function.

There can be many more reasons why the caregivers feel that the shubharthi should socialize. Now let us try and find out some realistic factors which the caregivers should consider while demanding that the shubharthi should socialize.

1. What is the occasion?

This will be very crucial factor. Why should the shubharthi be a part of this particular gathering or function? It can be a marriage, pooja, birthday party, anniversary, and celebration etc. of a relative or a friend or a neighbour. Try to find out how significant this function or the person concerned is for the shubharthi. If it is not then why should the shubharthi attend this function, when he/she doesn’t feel like?

2. What will be the shubharthis role in the function?

Try and imagine what will the shubharthi do in the function when you are busy talking, interacting with other people. If you see him/her sitting alone in a corner, not talking to anyone or just following you wherever you go without maintaining eye contact with others or he/she is restlessly fidgeting and looking nervous then ask yourself. 'Is it essential to force the shubharthi to come for the function?'

If the function is in the close family or your own family function then itis important that you discuss about it before hand with the shubharthi. Assign him/her a small task of his/her choice. Make him/her feel wanted and important. Keep a check on the shubharthi throughout the function, give positive feedback/ appreciation for his/her involvement. This may encourage the shubharthi to attend other function and gain confidence.

3. What is the illness stage of the shubharthi?

If the shubharthi is actively hallucinating, not slept sufficiently then it is not advisable to socialize for any occasion. In such scenario the first goal of the caregiver should be to gain control on the symptoms. Accordingly reporting to the doctor and adjustment in medication needs to be done.

4. How to go about having visits to the relatives or friends?

These visits should be planned after discussing with the shubharthi. He/she will like to know why he/she should visit this particular family, how long will the visit last, what is he/she expected to do. Discussing all these points and answering to the shubharthis queries is very important to make him/her comfortable with the visit.

5. Is it fine to take the shubharthi for a long or short trips?

We as families really like to enjoy going out on trips. Shubharthi may or may not be comfortable going out for trips. Important reason being that they have to get out of their comfort zone, out of the security of their house and travel. This in itself can be stressful. It is essential to discuss with the shubharthi of the travel plan, where to go, who all will be accompanying, which places are to be visited and other necessary details should be discussed with the shubharthi. Making him/her emotionally comfortable with the idea of travel is essential. Initially planning short trips with few people is recommended. If symptoms like hallucinations, delusions, hypersensitivity, mood swings are present avoid any trips or socialization.

Another aspect of socialization will depend on the level of functioning of the shubharthi. If the shubharthi is highly or partially functioning then he/she will be socializing as per his/her need. Doing the occupational duties taking up day to day roles and responsibilities in the family etc. He/she may prefer to be left alone many times but still will do the duties expected of him/her. In such scenario it is comparatively easy for the caregiver to negotiate with the shubharthi about the forthcoming social events.

When a shubharthi is non-functioning his interaction with the outside world becomes all the more limited. Motivating him/her to socialize becomes extremely challenging. It's advisable not to force the shubharthi to socialize in such a scenario.

Section IV

(C) Forming a support group.

Caregivers are fighting their own battle independently. They suffer alone. Many times, they want a person who would understand them, understand their troubles emphatically, just listen to their issues non-judgmentally. Caregivers are aware that there is no final solution to their problem, they just want someone to share and get support from. This is where the role of support group is very significant.

Why be a part of the support group?

Being a part of the support group has many advantages. You get a common platform to share your problems. All the people in the group are going through or facing a common challenge - taking care of a person suffering from schizophrenia. This common ground is sufficient enough for the people to come together. It is observed that the people learn from each other's experiences and sharing in the support group. The feeling that there is someone who is ready to understand and not judge in itself is very encouraging.

How to start a support group?

There can be different ways of starting a support group. For this moment to kick start one caregiver or a mental health professional has to take the initiative. We have lack of sufficient mental health professionals in India so it's better to depend less on their initiative. Caregivers themselves can take initiative and approach the treating doctor for help.

Firstly, if you yourself feel the need to talk to someone in the similar situation share it with your treating psychiatrist. Ask the doctor if he/she is aware of someone who would like to talk. Take the contact from the doctor. This can be the first starting point.

When you find such a person, you can decide on a date and time to meet. Place can be anyone's house, hotel or waiting room of the doctor (with his/her permission).

Second way of approaching it can be talking to the people in the waiting room whom you have seen earlier while you went for the follow-up. These casual talks can be very essential and helpful. You may find people who are interested in talking and sharing their problems. Also understand some people may be very secretive and like to keep to themselves. So avoid forcing such people to be a part of the support group.

Thirdly writing small articles about schizophrenia in local newspapers can also be helpful. Wait for people to contact you after reading the articles.

Fourthly you can make a small note of the purpose of the need to meet other caregivers and give it as pamphlets to your treating doctor. Request the doctor to give it to other families who have a shubharthi. Those who feel the need will contact you. This can be a good start for the support group. Your own openness to share, talk about the issue and revealing your own identity is extremely essential to make a start.

Fifthly look out for an established support group in your area and be a part of it.

Here facilitator can brainstorm with the group about other idea to start a support group. People in the group who stay close by can come together and meet in small groups.

Once the group of few members start meeting regularly purpose/mission of the group, different roles and responsibilities of the group members can be evolved.

How should an already existing group work and keep functioning?

a) Established group should meet regularly (at least once a month).
b) Roles and responsibilities of the members should be well-defined.
c) It's better if the group has a regular or visiting mental health professional attached to it.
d) Meeting the other treating psychiatrist around and informing about the group is necessary. Request them to refer interested or needy members to the group.
e) Different topics on schizophrenia, handling a person with schizophrenia, burden in the caregivers, effects of stigma and other related topics can be organised. These talks can be given by mental health professionals.
f) The support group can develop standard operating procedure in case of emergency in any family. First, second, third line of contact should be clearly mentioned.
g) The support group can work on procuring medicines at a concessional rate either from Pharma companies or the pharmacy nearby.
h) The support group can work out on helping the families develop a discipline follow up routine. This can be done by giving reminders, on actually going with the family for follow-up. This should be specifically done when the caregivers are very old and have no other support system.
i) Starting a rehab unit can be one of the agendas of the support group.

Starting Rehabilitation Unit:

Dealing with our non-functioning or partially functioning shubharthis is very challenging. No amount of motivation or provocation works. Some caregivers and volunteers need to come together and work on different ideas to motivate the shubharthis to come out of the house at least for 2 hours twice a week initially. Involving them in different activities which can be interesting like colouring, painting, making greeting cards, solving puzzles and some computer related activity if there is access to the computer etc. need to be

tried. Experience has shown us that only trial and error works. There is no fixed list of activities to start. It will depend on the interest and skills sets of that group of shubharthis.

On the other hand, people who are interested to work for a social cause are needed as volunteers to supervise this activity. Only caregivers may not have so much of strength and energy to consistently work for the group. These non-caregiver volunteers can be a great strength and support of this group. They can be given training about schizophrenia and the limitations it can cause.

Our experience at Tridal, our rehab unit has shown that these volunteers are a very good addition to the group. They bring with them new ideas and energies which is extremely essential for the functioning of the rehabilitation unit.

Section IV

(D) Question and Answers.

This section will deal with the questions commonly asked by the caregivers.

1. When can the shubharthi get married?

This is an important concern about many caregivers. In our Indian culture getting married and settling in life is essential. Due to the onset of schizophrenia completion of education, settling in job in itself gets delayed. Marriage is further delayed or at time we see many shubharthis stay unmarried.

Marriage is a huge responsibility and commitment. It comes with new roles and duties for which the shubharthi has to be ready. In many cultures if the shubharthi is a female it is not expected of her to be having a job or a career. But males need to be earning. Females are expected to take care of the household, serve the elders in the family and give birth to children.

Our shubharthi needs to be ready to take up all these responsibilities. It is recommended that the parents of the shubharthi reveal about the illness to the prospective bride or groom. There might be initial rejections but the party which accepts the proposal will be ready to walk the mile with the shubharthi. A spouse who is a part of the treatment process is always a great support to the shubharthi.

Before jumping to the decision of getting the shubharthi married, the parents need to assess the readiness of the shubharthi to be married.

If shubharthi is a male then how is he earning? Is he stable in his present job for at least two years? How is his socialization? Does he take up some responsibility in the day-to-day functioning of the household? All these and other related skills need to be assessed.

In case of a female shubharthi is she able to independently take care of the household responsibilities, including cooking, managing kitchen, managing finances, managing

relationships etc. is extremely essential. She is expected to be doing these duties at least for two years with complete responsibility.

Most important aspect of marriage is having healthy sexual relationship. It needs to be discussed with the shubharthi about the awareness of these aspect and readiness to have sexual relationship.

Telling the opposite party about the illness at the appropriate time, arranging a meeting between the treating doctor and the prospective family is crucial. Not revealing about the illness is considered as criminal offence in India.

2. Who will take care of the shubharthi after our death?

What after us? This is one of the most important and burning issue that the caregivers are bothered about. No one can predict when one will die. This thought trouble the caregiver very intensely. This thought causes severe anxiety especially when the shubharthi is non-functioning and totally dependent on the caregivers. Shubharthi may or may not have siblings. Even if the siblings are there they may be residing elsewhere or may not want to take care of the shubharthi. With all these uncertainties around it is better to start making the shubharthi as independent as possible. Make a list of things that the shubharthi is able to do - household responsibilities, doing work like going to the bank, shopping for day-to-day items, managing the follow-up with the psychiatrist, taking medication on time, doing basic cooking etc. On one level start working on making the shubharthi independent. This can be done with the help of a mental health professional or a person with whom the shubharthi is close to.

On second level make a ‘family trust’ for the purpose of taking care of the shubharthi. A lawyer, banks (e.g. Maharashtra Bank) help in setting up the family trust. 4-5 people from different age groups who are interested in the well-being of the shubharthi can become trustees. Mission of the trust will be to take care of the shubharthi till his/her death.

3. How to prevent relapse?

Relapse of the illness can be easily prevented. Make a note of all the symptoms of the shubharthi right from the onset of the illness. Check which symptoms are present and which symptoms are totally eliminated. Relapse is the recurrence of the symptoms. If you see that F-I-D of existing symptoms increases then immediately visit the doctor. If symptoms which were taken care of by the medicines are seen again report to the doctor.

4. Is schizophrenia hereditary?

When there is a parent who is suffering from schizophrenia or any other mental disorder then there are some chances that the next generation may suffer. If both the parents have any mental illness then the environment in the family is also affected. In such scenario chances of having any mental health issues increases. Hereditary is not a causative factor of

schizophrenia. Only cause known to the science is the neurochemical imbalance caused in the brain.

5. Can stress cause schizophrenia?

As mentioned above only known cause of schizophrenia is the neurochemical imbalance. Stress and different challenges in life can kindle some symptoms but not cause schizophrenia.

6. Can meditation cure schizophrenia?

No. Meditation does not cure schizophrenia. Schizophrenia is a thought disorder. While doing any form of meditation it is expected to concentrate on thoughts or gain control over thoughts. This is very challenging to the shubharthi. Only medication helps in gaining control over schizophrenia.

7. Does yoga and Pranayam cure schizophrenia?

Yoga and Pranayam can help in developing good health and wellbeing of the shubharthi. It will not cure schizophrenia.

8. Can fasting or doing different Pooja help in curing schizophrenia?

Fasting, worshipping, prayer in any religion is done for the satisfaction of the person who does it. It is not a cure for schizophrenia. As a caregiver if it gives you peace of mind, strengthen your mental ability, you can follow the practice. But the shubharthi should not be forced to do so. Also, while doing all these religious activities importance and significance of the medication should not be forgotten. Medication has to be given regularly to the shubharthi inspite of whatever religious activity you take up.

9. Is Homeopathy or Ayurveda useful to cure schizophrenia?

We have not come across any cases of schizophrenia which are cured by Homeopathy or Ayurveda. Allopathy is the treatment for schizophrenia.

10. How many people recover from schizophrenia? Is it an untreatable disease? Do people suffering from schizophrenia get sicker all their lives?

Schizophrenia has its own course and so the shubharthi takes time to recover from this illness. Schizophrenia is treated symptomatically and so recovery should be judged by the presence or absence of symptoms. There are some people who fully recover from this illness and may need treatment only for a short period. Some shubharthi recover and function fully with the help of the medication. Some shubharthis function partially with medication. These shubharthis need medication throughout their life.

Functioning of the shubharthi is a crucial aspect in understanding the recovery of that shubharthi. Gaining control over symptoms is also mandatory. Nearly 30 to 35% of shubharthi unfortunately cannot function even at a minimum level with medication.

11. Do people suffering from schizophrenia always get violent?

Getting abusive or violent is one of the symptoms of schizophrenia. This symptom is seen mostly in the active psychotic phase when the shubharthi is experiencing hallucinations and delusions. These symptoms are easily controlled by the medication. In under proper treatment shubharthi need not get violent or abusive.

12. Can people suffering from schizophrenia work?

Yes, many people suffering from schizophrenia are able to do full time-part time jobs or run their own business. Being constructively occupied helps the recovery process. In the initial phases the shubharthis may have problems with attention and concentration which can affect their work to some extent. With proper medical management they can work effectively. Shubharthis may not reach their earlier level of functioning. They should choose work according to their present level of functioning.

13. What role does faulty parenting play in causing schizophrenia?

There is no evidence to say that faulty parenting causes schizophrenia. Having a difficult childhood with abusive parenting style can cause lots of problems to the person. It can affect the emotionality of the child to a great extent. Expressed emotionality of the caregivers and their communication pattern (lack of empathy) plays a very significant role in the recovery process of the shubharthi i.e. it affects the recovery in a negative way.

14. What are the medicines given to the people suffering from schizophrenia? Are they only sedatives?

Our shubharthis are treated with the medication that will reduce their psychotic symptoms and gain effective emotional control. In some cases, the patient is unable to sleep properly for many nights. This is when they are given some medicines to get good sleep. All anti-psychotic medicines are not sedatives.

15. Are personality disorder and schizophrenia same?

No personality disorder and schizophrenia are not same. Schizophrenia is a thought disorder. There are range of personality disorders classified by the mental health professionals. To simplify it we all have personalities which help us to achieve our life goals or hinders that progress. When the progress of attaining life goal is hindered, it causes a lot of stress in the person's life and family. After a series of such episodes of problematic personality is developed. This is totally different than what schizophrenia is. Some symptoms of schizophrenia can be observed in people with personality disorders.

REFERENCES for REBT and for other issues that caregivers need to deal with. (eg, addictions such as drinking, gambling, etc.)

Albert Ellis

- Albert Ellis and Robert Harper (1961) A Guide to Rational Living
- Albert Ellis and (1981) Rational Emotive Behaviour Therapy
- Albert Ellis (2001) Overcoming destructive beliefs, feelings and behaviour.
- Albert Ellis and William Knaus (1977) Overcoming Procrastination
- Albert Ellis (1993) When AA does not work for you.
- Albert Ellis and Emmet Velten (1992) Rational steps to quitting alcohol.

Paul Hauck

- Overcoming Depression (1973)
- Overcoming frustration and Anger (1974)
- Overcoming worry and fear (1975)
- Why be afraid (1984)
- Depression (1979)
- How to be your own best friend(1988)