



# NAE UMEED

Strengthening community-based caregiving



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- Women’s Health.gov: <https://www.womenshealth.gov/publications/our-publications/fact-sheet/caregiver-stress.html>
- Project Burans site: <http://projectburans.wixsite.com/burans>
- Caregiver Stress & Burnout: Tips for Regaining Your Energy, Optimism, and Hope: <http://www.helpguide.org/articles/stress/caregiving-stress-and-burnout.htm>
- Metaphors for Therapy: <http://www.getselfhelp.co.uk/metaphors.htm>
- Who’s Who and the New: <http://www.whoswhoandthenew.blogspot.com>

Layout & Graphic Designed by - Suanlian Tangpua, EHA

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## How to use this Manual

This manual is a resource to facilitate community-based groups of caregivers of people with psycho-social disability. The nine modules each has a focus on an aspect of knowledge and skills useful for caregivers. The following table gives an overview of guidelines we have found useful in leading caregiver groups.

<p><b>Why do caregivers need a support group, and what will they learn at the group?</b></p>	<ul style="list-style-type: none"> <li>■ Being a caregiver for someone with a mental illness is a unique position with particular rewards, challenges, issues and concerns.</li> <li>■ Caregivers can increase social support and knowledge in meetings with other caregivers</li> <li>■ In a facilitated group, caregivers can learn information, skills and approaches that will assist them in this role.</li> </ul>
<p><b>Who should be invited to join a caregiver support group?</b></p>	<ul style="list-style-type: none"> <li>■ Anyone who is providing care for someone with psycho-social disability or who would like to join.</li> <li>■ Try to form groups with people who live near each other and who are from the same communities</li> <li>■ Usually group participants are more comfortable sharing if people in the group are of the same gender</li> </ul>
<p><b>How often should the caregiver group meet?</b></p>	<ul style="list-style-type: none"> <li>■ The group should meet regularly as time and availability allows ideally at least once a month.</li> <li>■ Group members should make a commitment to attending all sessions</li> <li>■ Each module is expected to take one hour to complete.</li> </ul>
<p><b>How often should the caregiver group meet?</b></p>	<ul style="list-style-type: none"> <li>■ Any community based person who can read and write</li> <li>■ A three day training in group facilitation and covering the subject matter of these modules is helpful to ensure group facilitators use interactive and participatory methods</li> </ul>

**Table 1: Useful guidelines for forming caregiver groups**

## Timeline

<p><b>Weeks prior to starting caregiver group</b></p>	<ul style="list-style-type: none"> <li>■ Identify the caregivers that can come to the group.</li> <li>■ Meet and discuss a suitable time and venue for the group to meet.</li> <li>■ Make sure the venue is appropriate, large enough for all members with limited interruptions and few onlookers.</li> </ul>
<p><b>The Day Before the Meeting</b></p>	<ul style="list-style-type: none"> <li>■ Read through the module that you will be delivering the next day.</li> <li>■ Ensure venue is confirmed.</li> <li>■ Resources: Make sure you have any resources you need.             <ul style="list-style-type: none"> <li>● What you need is listed at the beginning of each Module. Resources include large paper and marker pens, pamphlets etc.</li> </ul> </li> </ul>
<p><b>How often should the caregiver group meet?</b></p>	<ul style="list-style-type: none"> <li>■ Make sure you arrive at the venue on time and be prepared with the resources your prepared yesterday.</li> <li>■ Make sure all members are welcomed and made to feel comfortable.</li> </ul>
<p><b>How often should the caregiver group meet?</b></p>	<ul style="list-style-type: none"> <li>■ Each week/topic should be introduced at beginning of session and recapped and reviewed at the end of the session.</li> <li>■ If homework assignments were set last session, ensure these are reviewed in this session.</li> </ul> <p><b>Timing</b></p> <ul style="list-style-type: none"> <li>■ Each session should last around one hour.</li> <li>■ Try to manage activities so that there is time for all that is planned for each module.</li> <li>■ Sometimes important additional discussion topics arise – give time to discuss them if they are relevant and useful for most people and if needed adjust the programme to give participants opportunity to discuss what they find important.</li> </ul> <p><b>Equal Participation</b></p> <ul style="list-style-type: none"> <li>■ Make sure all members of the group participate equally.</li> <li>■ Some members will naturally talk more and dominate the group.</li> <li>■ Allow the shy people on the group to share as well.</li> </ul> <p><b>Format</b></p> <ul style="list-style-type: none"> <li>■ Focus on interactive and participatory approaches using the prompt questions in the manual to start discussion</li> <li>■ Many questions have more than one correct answers.</li> </ul>

## Module One: What is a Caregiver?

### Aim of Module:

- For all participants of the group to get to know each other in a welcoming environment.
- To understand the reason and purpose for the group.

### Aim of Module:

- Large Paper
- Marker Pens
- Appropriate Venue

### First Activity

- Introduce yourself and the purpose of the Group.
- Introduce yourself & and the NGO/ project you represent
- Explain that everyone there provides care for someone with mental illness.
- Celebrate the unique and important role that caregivers play in the lives of people with mental illness.
- Explain that the group will share ideas and experiences of being a caregiver.

### Second Activity

- Arrange group members into pairs.
- Each person takes turns at interviewing their partner
- The questions are:
  - What is your partner's name?
  - Who do they care for?
  - What do they hope to learn from the group?
  - One interesting fact about the other person
- Once completed, come back to a large group, where each person introduces their partner.

### Learnings from Activity

- Highlight that in this activity participants used listening skills and recalled key information.

### Third Activity – Who, What Why, Where, When

- Encourage, thinking and discussion about their role as a caregiver.
- Provide the facilitator with an indication of the group's existing knowledge.
- This can either be a group discussion or divide the group up into smaller groups.
- Use large sheet of paper to write responses.
- Questions could include:
  - Who is a caregiver?
  - What is the reason your relative requires care?
  - Why is your relative like this?
  - Where do you get support?
  - When should you ask for help?

- You can rephrase these questions.
- Get the group to discuss the knowledge they have.
- Think about signs and symptoms of mental illness, and why their caregiver role is significant.

### Learning from Activity

- This activity will provide a focus for the information that will be given throughout the course.
- Keep the paper and bring it to the last session for review. Reviewing at the last session will highlight the changes in knowledge that the group members have.

### Activity Four

- Introduce the topics for coming weeks this should reinforce the previous discussion.
- Write up/distribute a list of upcoming topics for next sessions.
- Discuss each topic briefly with the group (do not go into depth, as it is just to introduce them):
  - What is mental illness?
  - Medication
  - How to treat someone with a mental illness
  - Alcohol and health
  - Stress
  - Self-Care
  - Summary of sessions

### Activity Five

- Discussion expectations, and produce an agreed set of rules.
- One suggestion is that at each session the community worker will take attendance register.
- Sample shared group rules:
    - We all try to be on time and attend every session
    - We respect and listen to each other in group meetings
  - We do not share the discussions from these meetings with others
  - Write down the shared group rules and keep these visible in meetings for reference

### Conclusion

Ask group members to return to their pairs from the beginning of the session. Ask each pair to discuss:

- What have they have learnt from today's session?
- What topic in the coming weeks they are most looking forward to and why?
- Are there any questions about what they learnt today?

Finally, ask each person to share the discussion from the partner with the group. Thank everyone for coming and remind of the time for next week.



## Module Two: Mental Illness

### Aim of Module:

Group members will learn:

- What is mental illness?
- What are the symptoms?
- What are the behaviours?

### Aim of Module:

- Large Paper.
- Marker Pens.
- Appropriate Venue.
- Copies of the diagrams to hand out to the participants.
- Think about other resources you have in the office that may be able to assist you with this week's topic.
- Pictures, diagrams, handouts.

### First Activity

- Welcome everyone.
- Do a round of introductions, when each person introduces themselves saying:
  - Their name;
  - One good thing that happened during the week; and
  - One thing they remember from last week's session.

### Activity Two – Human Knot Exercise

- Get all group members to stand in a circle (standing very close to each other).
- Each person lifts up their left arm and holds hands with someone else in the circle.
- Repeat above with right hand and join hands with a different person.
- Each hand joins with a different person and cannot be the person beside them.
- This will create a human knot or mix of crossed arms.
- The group members must keep holding the hands at all times and not let go.
- The aim is to work together, move and communicate to go back to the original circle.

### Link to this Week's Topic:

- When finished discuss what they thought of the activity.
- Did you have to think about what actions you needed to take to untangle yourself?
- General discussion.

### The Learning from this Exercise:

- To do the above activity members were heavily reliant on their brain.
- The brain is important.
- The brain controls our thoughts and our actions.



***Mental illness is caused when a person has had difficult childhood or social experiences and disadvantage, and also can be due to a higher risk in some families as well as reasons that we don't understand. These causes impact the way that the brain works.***

### The Importance of the Brain

#### *Brain chemicals:*

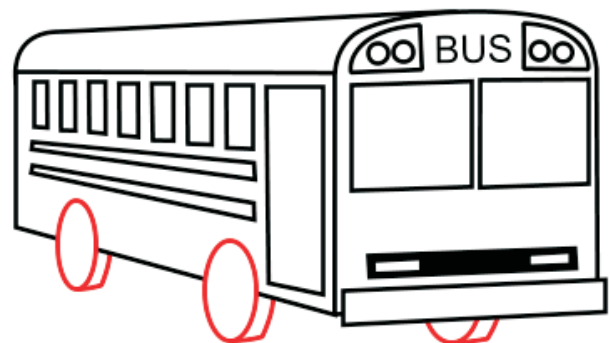
- Are like fertilisers for the brain
- Help the brain to grow
- Like petrol makes the car run

#### *The brain controls:*

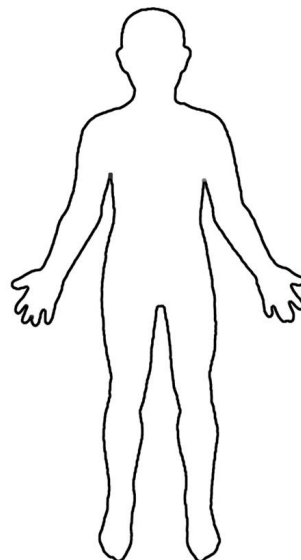
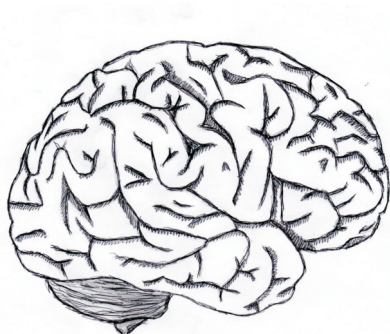
- Everything we do
- Everything we say
- The way we live our lives

**We need our brains working well for physical and mental health.**

Use the following images to demonstrate the role of the brain :



The bus driver is responsible for driving the bus.  
The brain is responsible for driving the body.

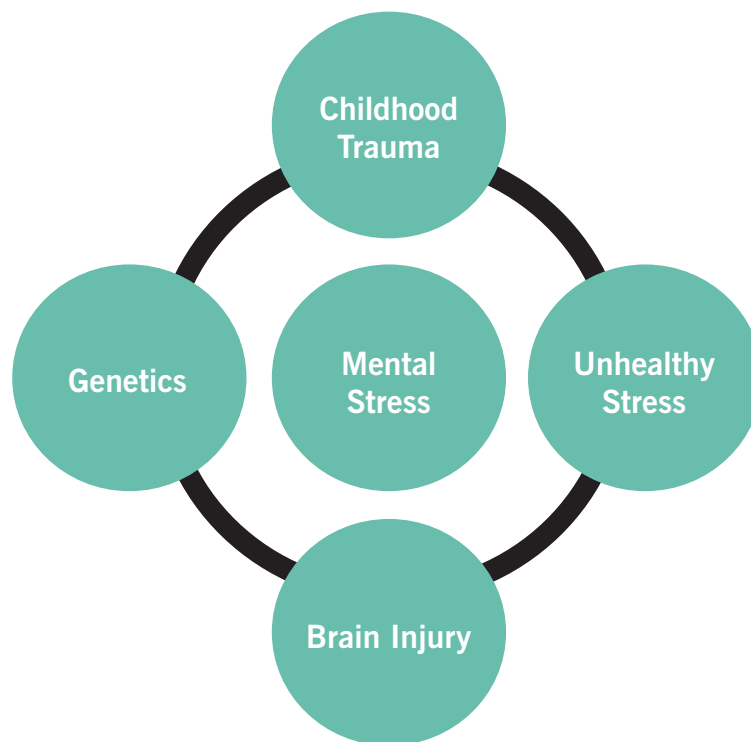


### Questions to Discuss with the Group

- What happens when the Bus Driver can't/doesn't go to work?
- What happens to the Bus?
- What about the passengers on the Bus? What happens to them?
- What happens when the Brain can't/doesn't work?
- What happens to the body?
- A brain is unwell or that is not working is an indication of a mental illness.

### How does the brain become unwell?

Ask group members to get into pairs and discuss how they think a brain becomes unwell. Draw this diagram and explain that there is no one cause of mental illness but many causes.



**Genetics:** Your brain is Similar to that of a direct relative. Sometimes mental illness can be passed on from one generation to another. This is because a person brain is built during the time of pregnancy. If there are previous problems from blood relatives it can affect how the brain is built.

**Childhood trauma:** Physical abuse, accidents, illness – not getting the care and attention that is needed when you are a child.

**Brain Injury:** Accidents, motorbike accident, hit to the head, medical injury, stroke, lack of oxygen.

**Unhealthy Stress:** Tension and worries, fear and unhappiness, cannot solve problems, unreasonable expectation and demands on themselves and others.

### How would you know if someone had an unwell brain?

What would they be doing? What would they be saying? What would their behaviour be like?

Copy this diagram on large piece of paper and discuss behaviour of a person with Mental Illness.



#### It is important to inform the group that:

- Mental illness is not caused by evil spirits or black magic.
- Mental Illness is nobody's fault.

Remember the mentally stressed person has little control over their symptoms. They did not cause them and need help to deal with them.

#### Third Activity – QUIZ!!

Divide the group into two teams. You can decide either to go through the answers after you have asked each Question or you can go through all answers at the end like a test.

#### Quiz Questions:

1. True or False: anyone can get a mental illness?

**Answer** = True

2. Name three behaviours someone with a mental illness may have?

**Answer** = talking to self, laughing, shouting, aggression, reduced social contact, any unusual behaviour, staying in bed, saying words over and over,

3. Is a mental illness a punishment for something they have done wrong?

**Answer** = No

4. True or False: mental illness is related to a problem in a person's brain.

**Answer** = True

5. Name three people you can talk to for help about your relative's mental illness.

**Answer** = Family and friends, community worker, doctor

6. Can you catch a mental illness like you catch a cold.

**Answer** = No

7. Name three ways you can get a mental illness.

**Answer** = see above activity

**8.** Is a mental illness caused by evil spirits.

**Answer** = No

**9.** Name three things that may help someone with a mental illness.

**Answer** = Take time to listen well, helping them keep a regular sleeping and eating pattern, talking in a quiet calm voice, not disagreeing with them, being kind and other sensible answershgfdM.

**10.** What are three signs of depression?

**Answer** = sad mood, loss of hope for the future, thoughts of suicide, reduced social engagement, early morning waking or general sleep disturbance, negative thinking

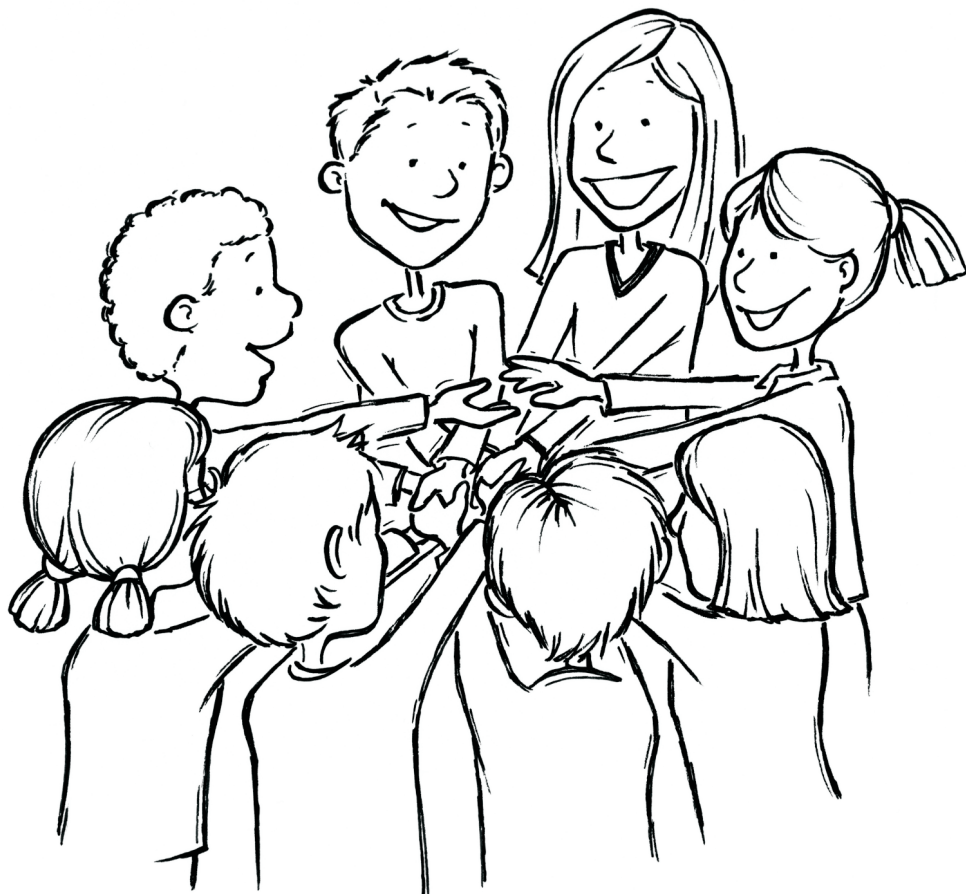
### Conclusion

- 3,2,1 Exercise<sup>2</sup>.
- Go around the group and ask everyone for:
  - Three things you have learned today.
  - Two questions you still have.
  - One Idea that has stuck with you from today's session.

### Homework

- Discuss the understanding of mental illness with two family members.
- Share with their family and friends what they have learned at the group.

<sup>2</sup> <http://www.whoswhoandthenew.blogspot.com>



## Module Three: Caring for Someone with Mental Illness I - Communication Skills

### Aim of Module:

Understanding the importance of communication in managing your relative's mental illness.

### What you will need:

- Large Paper
- Marker Pens
- Appropriate Venue
- Winning Ways to Wellbeing handout
- Pamphlets, such as those developed by EHA: Strong and Positive Family Interactions to Build Positive Behaviour and Actions
- Any other pictures, diagrams, handouts you think would be useful

### First Activity

Go around the group and invite them to each share:

- One highlight from the previous week OR
- One thing they found memorable from last week's session

### Second Activity – Birthday Sequence

- Indicate an imaginary line running the length of the room.
- The line indicates age. One end of the line is age 20 (for example, can use any age) and the other end of the line is age 100.
- Group members organise themselves in order of their age.
- Everyone has to be standing single file, in order from oldest to youngest
- But they need to do this without talking. The group has to use other methods of communicating.
- Once a line has formed and it appears that this task has been completed, start at the one end and ask everyone to say their age out loud.

### The Learning from this Activity

- How much we rely on spoken communication.
- Communication is essential when caring for someone with the mental illness.
- This activity demonstrated:
  - When we know what they want to communicate but are unable to do so.
  - Can the group think of a time that this has occurred for them or their relative?

**Introduce this Week’s Topic**

Explain that how we treat our relative is important to managing their mental health. Ask participants to discuss their experience of a particular challenging behaviour they have experienced in their relative. Ask each member of the group to share and experience that they have had when the behaviour of their relative brought up particular emotional reaction. The reaction could have been, scared, sadness, embarrassment. For example, Poonam cares for Sanjay. One day at the market Sanjay became upset and shouted and caused a scene. Poonam was embarrassed. She did not want to tell anyone what happened so she has been worrying and been upset about the incident since it happened.

Maybe members of the group have had similar experiences. Something may have happened that they experienced being scared or frightened by their relative. Ask the group to discuss their experience of particular behaviour they have experienced from their relative.

**Communication**

Briefly describe the different ways we communicate. These are summarised in Table 2.

**Table 2: Types of Communication**

Verbal	Speaking/shouting/whispering
Non-Verbal	Facial expressions, such as frowning or smiling
Body Language	Rolling eyes, crossed arms, hugs, touches of affection
Emotional Outbursts	Slamming doors, silent treatment

**Third Activity**

Ask each member of the group to share:

- An example when they have had difficulty communicating with their relative.
- What did they try to overcome the difficulties they were experiencing?
- Can you think of some reasons why communication may be difficult for your relative?
- The chemical imbalances in the brain mean the brain does not operate as it should.
- The message from the brain to communicate is damaged.
- Side effects of medication may also affect communication.

## Module Four: Caring for Someone with Mental Illness II – Interaction

### Aim of Module:

Understanding the importance of interaction and behaviour in managing your relative's mental illness.

### What you will need:

- Large Paper
- Marker Pens
- Appropriate Venue
- Winning Ways to Wellbeing handout
- Project pamphlets, especially: Strong and Positive Family Interactions to Build Positive Behaviour and Actions
- Any other pictures, diagrams, handouts you think would be useful

### First Activity

Go around the group and invite them to each share:

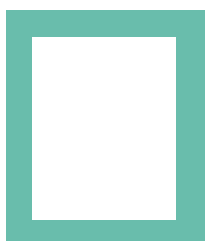
- One highlight from the previous week.
- One thing they found memorable from last week's session

### Techniques for Behaviour Modification

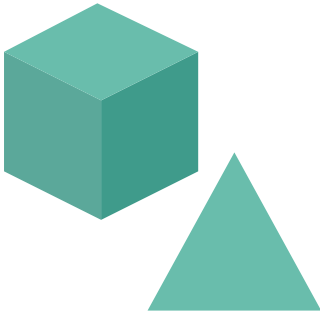
The following three techniques are suggestions of strategies that caregivers might adopt to manage or modify the challenging behaviours of their relatives with mental illness.



**Positive reinforcement** is a strategy to guide behaviour where desirable consequences are given for positive behaviour with the intention that behaviour will be repeated. Rewarding positive behaviour and ignoring less desirable behaviour. Give an example of how we might reward a child's good behaviour by praising them in front of the others in the family – saying specifically what you noticed them doing – and then giving them the first serving at dinner time.



**Modelling/mirroring** Is a process when desirable behaviour is deliberately displayed. As a caregiver you can demonstrate the behaviour. For example, talk about how often people who are mentally distressed with anxiety or psychosis often say something irrational or unreasonable, yet we need to choose to be respectful and not react to what they say and just agree or change the topic carefully. We can model this to others in the household.



**Shaping.** As a caregiver you should not do everything for your relative. Ask your family members to help and explain clearly your expectations and their responsibilities. Shaping is the idea that you support new behaviour in the right direction – e.g. starting to take steps to take a bath, even if they need help with getting hot water or shampoo is a good start. Slowly you help build up steps taken to complete the desired behaviour. Use a care plan to as a tool to shape their behaviour.

### First Activity – Role Play

The purpose of this role play is to practice and demonstrate the three types behaviour management strategies discussed above.

The facilitator will choose a member from the group to participate in the role play with them.

The volunteer from the group will:

- Play/act like their relative with a mental illness.
- Play/act with difficult or challenging behaviour.

The group facilitator will:

- Play/act the role of the caregiver.
- Demonstrate examples of the behaviour management strategies above.

As there are three different behaviours, the role play will be carried out three times; ask for a different volunteer from the group to participate for each behaviour.

- The first time the facilitator demonstrates **positively reinforcing** behaviour.
- The second time the facilitator demonstrates **modelling** behaviour.
- The third time the facilitator demonstrates **shaping** behaviour.

After the first round of demonstrations, either repeat the exercises where the group member is the caregiver and the facilitator acts as the relative, or break the group into pairs and ask them to practice by taking turns. Facilitator circulates the room and supervises.

### Learning from Activity

The activity should demonstrate different strategies that caregivers can adopt to modify and manage the difficult behaviours in their role as caregivers.



## Routines

Routines are important for PPSD so that things are predictable and to develop patterns. An example is developing a regular morning routine where they have a clear understanding of what they need to do and what activities are taken.

- 7am Rise from bed and fold up all sheets and blankets and keep in trunk
- Brush teeth, wash face, comb hair
- Go for 30 minutes morning walk
- 8am Chai is given to all family members
- Sweeping of the front family room, the aangan and in front of the house and give water and food to any animal
- 9am Breakfast

A regular routine where each family member knows what is their responsibility and all are expected to help and contribute to household responsibilities is a way that can help all people in the household to develop good habits. Ask group members to discuss in pairs the following two topics:

- what routines they already have in place to help their family members
- an idea for a new routine they would like to put in place that might be helpful for their family member

## Conclusion

Summarise the session:

- Demonstrating good behaviour is an important way to modify the behaviour of individuals with mental illness.

Ask the group to move into pairs and ask them to discuss:

- The most interesting thing they learned today.
- What are two things they learned in today's discussion that they would like to try to start using at home this week. Ask them to describe as specifically as possible.



## Module Five: Medication

### Aim of Module:

To understand what is required for successful treatment of their relative with a mental illness.

### What you will need:

- Large paper
- Marker pens
- Appropriate venue
- Copy of care plan used for clients (one that has not been filled out yet)
- Any resources or diagrams about medication

### First Activity

- Introduction activity/recap last week.
- Do introductions again if any new people have come.
- Go around the group one at a time and ask about what new activity they tried for managing behaviour from last week and how things went trying to use it.

### Second Activity – Telephone Connection (Warm-up)

- Everyone sits in a circle.
- One member of the group thinks of a basic sentence. For example: “Today is a sunny day!”; “This is my favourite sari.”
- This person DOES NOT say it out loud.
- They whisper it directly into the ear of the person beside them.
- It continues to be whispered to each member until it reaches the person who originally said it.
- The last person to hear the sentence (not the person who made it up) repeats it out loud to the group.
- Compare and discuss the different statements.

### Learning from Activity

Point out to the group that it is important that when dealing with people with Mental illness key information needs to be shared is accurate.



### Medication and Side Effects

Sometimes when the brain is unwell, it is like any other illness and medication is required.

- In a group discussion ask these questions:



### Important Points to Explain to the Group:

- Medicine helps to control symptoms of mental illness, but **not everyone needs medication.**
- Medication only works if it is taken every day as prescribed by the doctor and until the doctor instructs that the medicine is no longer required. Sometimes the medicine is needed for months and sometimes for years.
- If you don't follow the advice of the doctor, the medication will not work in the way that it is meant to. **If the patient takes more than what the doctor prescribes, it can make the patient very sick.**
- Explain how the medication works, by increasing brain chemicals. [Use white board drawing]

**Table 3:** Side Effects of Medication

Side Effect	Suggested Response
<b>Dry Mouth</b>	Chew gum, suck fruit stone or sip water.
<b>Constipation</b>	Drink at least two litres of water a day. Eat plenty of vegetables and fruit and eat less rice.
<b>Nausea</b>	Take medication with food.
<b>Headache</b>	Drink plenty of water. If it does not stop after two weeks, tell the doctor.
<b>Dribbling</b>	Tell the doctor and use two pillows at night.
<b>Rash</b>	Tell the doctor.
<b>Weight Gain</b>	Eat only three meals a day. Use less oil and sugar. Nibble on raw vegetables or drink water. Stay active and exercise.
<b>Increased Sleepiness</b>	Ask doctor about dosage and review of time of day medication is taken.
<b>Increased Restlessness and Irritability</b>	If occurring at night, take evening doses earlier. Discuss with doctor if it persists.

You can always discuss the side effects with your doctor and ask ascertain what options are available. Maybe a different medication, or changing the dosage may be a solution.

**Figure 1: Facts about Medication**



**Encouraging a Relative to Take Medication**

Encouraging a relative to take medication can be difficult, particularly when your relative does not want to take it. Ask the group to share times when they have tried to help their relative take medication but they have refused. What happened? Ask if they have tried the techniques discussed in last week’s session, such as modelling shaping and mirroring to assist their relative in taking their medication.

**Stress the importance of care giver closely supervising taking of medication.**

When the person becomes well, they may be able to take responsibility for this.

**Following to treatment plans**

The facilitator should show the group a sample of an empty care plan if the group members are not familiar with it.

If the group has any queries about medication management they can refer to:

<b>Doctor</b>	<ul style="list-style-type: none"> <li>■ It is extremely important that caregivers go to doctor appointments with their relative.</li> <li>■ You need to hear what the doctor’s advice is so you can assist your relative in their medical treatment plan.</li> <li>■ Due to the way your relative is feeling and the symptoms of their mental illness, he/she may not always tell you all the information and/or be honest with you about what the doctors advise is.</li> </ul>
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**Community Worker/Community Team Member (ask who the group is in the community that can assist and help)**

- The local community worker/team have provide a care plan for your relative which covers all aspects that we have talked about today (medication and self-care).
- It is important you work together with your community worker; your relative's recovery will be greatly improved if you adhere to the care plan.

### Conclusion

Divide the group into pairs and ask them to discuss the following:

- What are the important things to remember about medication?
- What have they learned about side effects?
- What other things can help manage their relative's illness?
- Who can help you stick to the prescribed treatment plans?
- What was the biggest learning from today?

Finish the session by reminding the group of a time and place for next week.



## Module Six: Alcohol and Health

### Aim of Module:

Learn about alcohol abuse is and the how it impacts their relative and their family.

### What you will need for the session

- Large paper
- Marker pens
- Appropriate venue
- Copies of diagrams used in this session to hand out to participants
- Any resources or diagrams about alcohol that you may wish to give
- Information on local Alcoholic Anonymous in your area

### First Activity – Warm Up

- Sitting in a circle, ask each person to share:
  - One highlight of the past week
  - One challenge/difficulty they have had in the past week
  - Something that the rest of the group may not know about them.

### Second Activity – Recap Last Week

- Discuss last week's topic of medication and treatment plans.
- Ask the group what they remember from last week's session
- Did they put any of the learning from last week into practice during the week?

### Introduce this Week's Topic

This week's topic is alcohol abuse. Do a brainstorm exercise and write up answers on a large piece of paper. Questions to aid discussion:

- What is their understanding of alcohol abuse?
- Does their relative drink alcohol?



**Alcohol becomes a problem when:**

- When people say they “need” or “have” to drink.
  - For example, “I have to drink in order to sleep or relax.”
- When people are drinking alcohol every day.
- When they are drinking large amounts of alcohol every day.
- When they are spending money on alcohol and there is no money for food or rent.
- When their behaviour and personality changes after drinking alcohol.
  - For example, is they may become violent and aggressive, loud and disturb other members of the household.

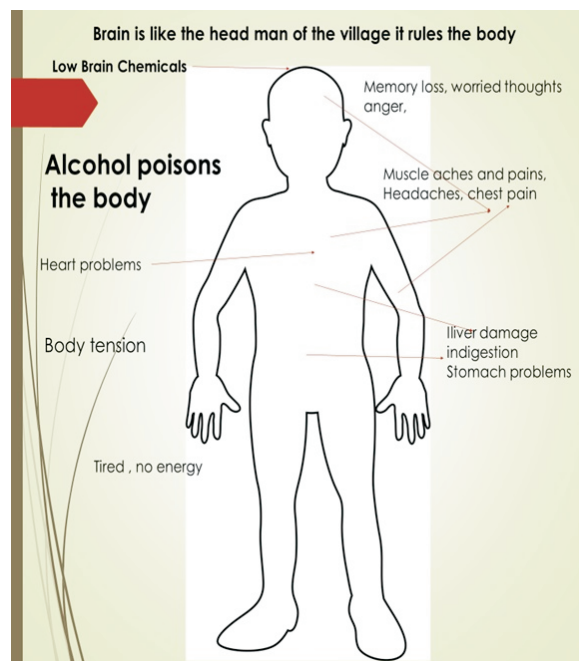
***When the use of alcohol becomes a problem, your relative is doing serious long term damage to their health.***

**The Effects of Alcohol on the Body**

Draw a person’s body on the board, ask for ideas about how alcohol may harm the **body and emotions**.

Now write on the diagram and explain:

- How alcohol affects the body: the brain, memory, stomach, liver and heart, and how it lowers the brain chemicals so that the feelings and mood are affected in a bad way.
- Alcohol poisons the body.





### What impact does alcohol have on people who are taking medication?

- Last week we discussed medication, the reasons people take medication, and the importance that medication can have on managing the symptoms of mental illness

Ask the Group:

- What do you think would happen if someone who was taking medication prescribed by the doctor was also drinking alcohol or other drugs/substances?

Brainstorm ideas/answers on the white board/large piece of paper.

***If your relative is taking medication, they should not drink alcohol. It will make the symptoms of their mental illness worse.***

### Recap Main Ideas

Alcohol and other substance use is not beneficial for someone with a Mental illness  
 People may think alcohol helps them but long term use makes the symptoms of their mental illness worse  
 People who drink alcohol when they are taking medication are going to make themselves sicker.

### Conclusion

- Divide the group into pairs and ask them to do the 3, 2, 1 exercise from the earlier module.
  - 3: Discuss three things they have learned today.
  - 2: Discuss two ways they will put what they have learnt into practice
  - 1: Ask for any questions they still have.
- Bring the group back together and ask them if they wish to share anything they discussed in their pairs.



## Module Seven: Managing Stress

### Aim of Module:

Understanding what stress is and how to manage it.

### What you will need:

- Large Paper
- Marker Pens
- Appropriate Venue
- Pamphlet titled: Care for yourself too in the Appendix.
- Any resources or diagrams about stress
- YouTube link of Five steps to wellness movie clip

### First Activity

Welcome everyone to the group.

Go around the group and ask each group member to say one thing that that learnt from last week's session and/ Or one thing they did differently during the past week.

### Introduce this Week's Topic

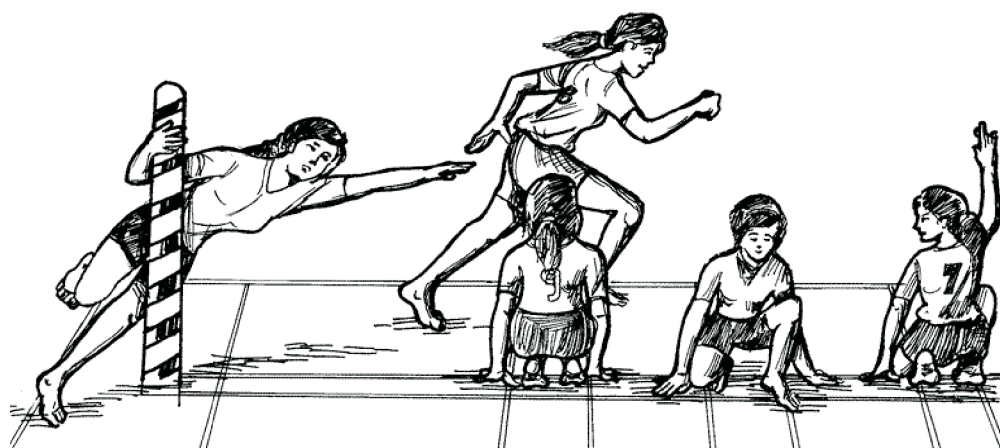
This week's topic is Caregiver Stress. Ask the group how they understand caregiver stress.

- Brainstorm the ideas on large piece of paper.
- Divide the group into pairs and get them to discuss two good things about being a caregiver and two bad things about being a caregiver.
- Bring the group back together and talk about the points that came up in the discussion in pairs.

### Being a caregiver can be great!!!

Some of the benefits are that it is:

- Rewarding
- A Privilege
- Fun
- Provides a purpose
- The group may have come up with their different benefits. Add them to the list if necessary!!



### Second Activity

- Ask the group to discuss how being a caregiver is the same as having a paid job.
- Brainstorm answers on the large sheet of paper.
- If the group needs assistance with the answers some tips might be:

Caregivers	Paid Employees
Are relied upon to provide care	A boss relies on his employees to do work
Are expected to provide care	A boss expects employee to come to work
The care won't be provided if you don't do it	If you don't go to work, the work won't get completed

There is one major difference between paid employment and caregiving (other than the pay):

- Employees go to work, and then they get to go home
- Caregivers live where they work and are constantly living with their caregiving role.

### Important Points for a Caregiver:

- Explain to the group that every person only has a certain capacity for the amount of stress that they can handle:
- Each person has a different level.
- The amount of stress one person can manage will be different to the next person.
- Whatever the amount of stress you can manage, it is important not to deplete yourself.
- Think of your ability to care for your relative to be like a water tank.
  - The more you take from the tank the less you have to give. At some point you need to replenish or top up the amount of water in the tank.
- As a caregiver you cannot continuously give, give, give, to others: you have to take time for yourself as well.
- It is important to recognise when your stress becomes a problem. Your stress will be a problem when your internal water tank is completely depleted. This is often referred to as Caregiver Burnout<sup>3</sup>.

<sup>3</sup><http://www.helpguide.org/articles/stress/caregiving-stress-and-burnout.htm>

### Discuss everyday stress vs. unhelpful stress

It is impossible to get away from stress. Every single person on the planet has experienced stress. Stress is common.

#### Examples of Everyday Stress

Let the group discuss everyday stresses they experience. The facilitator may want to give an example of stress they experience, report writing for work, possible commitments they have in the community such as running events at church. There could be many examples:

**Getting the children ready for school** (awake, breakfast, dressed and at school on time)

**When something useful breaks down** (washing machine or phone)

**Playing sport** (the desire to play well, win the game and not wanting to make mistake)

#### Unhelpful Stress

Unhelpful stress is when the stress continues long-term. In the examples of everyday stress above, these experiences usually only occur for a short time.

Stress becomes a problem when:

- It continues for a long time.
- It disrupts you being able to function in everyday life (eating, sleeping, doing things you enjoy).

### Discussion – Recognising Caregiver Burnout/Depletion

Get the group together to brainstorm ideas, writing them up on whiteboard or a large piece of paper.

#### Tips for Activity

Some indications of burnout may be:

- Depression
- Feeling anxious
- Worried
- Changes in sleeping and eating patterns
- You are not enjoying anything about being a caregiver
- Withdrawing socially from other people
- Stopping doing the things you enjoy.
- Not wanting to do your daily chores (housework, shopping)

#### Learnings from the Activity

- Ask the group if they can think of similarities between caregiver burnout and the mental stress their relatives experience.
- Do any of the brainstormed ideas or the list provided also apply to the way their relative may act when they are unwell with their mental illness?
- Note that the signs and symptoms of caregiver stress can be the same as those their relative experiences.

### Fifth Activity – Managing Burnout

Remember, if you are well, your family can be stronger and healthier too.

- What can you do to help prevent coming unwell?
- What information and skills from previous sessions can you use?

Discuss the table below with the group and ask participants to come up with their own examples.

Table 4. Suggestions for Managing Stress

Things to Help Reduce Stress	Learnings from Previous Weeks
<ul style="list-style-type: none"> <li>■ Focus on the good things or the things you enjoy about being a</li> </ul>	<ul style="list-style-type: none"> <li>■ Remember to give thanks/ gratitude for what you do have. Celebrate all the good points about your relative.</li> </ul>
<ul style="list-style-type: none"> <li>■ Focus on what you can do rather on what you can't do.</li> </ul>	<ul style="list-style-type: none"> <li>■ Behaviour management techniques that you have learnt, positive reinforcement, modelling behaviour.</li> </ul>
<ul style="list-style-type: none"> <li>■ Celebrate small successes.</li> </ul>	<ul style="list-style-type: none"> <li>■ Reward yourself when things go well.</li> </ul>
<ul style="list-style-type: none"> <li>■ Congratulate yourself.</li> </ul>	<ul style="list-style-type: none"> <li>■ Give thanks, recognise the work you do for your relative.</li> </ul>
<ul style="list-style-type: none"> <li>■ Get help from others.</li> </ul>	<ul style="list-style-type: none"> <li>■ Share the responsibility of the caregiving role with others.</li> </ul>

Overall, there are two important ways to manage caregiver burnout:

- Taking care of yourself (this is covered another Module); and
- Taking a break.

### Sixth Activity

Brainstorm the ways you can have some time away from relative. Possible suggestions include:



### Conclusion/Recap of Session

- Review the main points, signs and symptoms of caregiver stress and ways to manage these.
- Divide the group into pairs and ask each pair to discuss what was the most memorable thing they learned today.

### Homework:

Ask each member of the group to go home and:

- Identify a friend or family member who they can ask to help them with the caregiving duties.
- Share with that person what you have learned at the caregiver group and how you want that person to help you.
- Next week you will be asked at this group to report on this discussion.

## Module Eight: Self-Care

### Aim of Module:

For all participants of the group to understand:

- What is meant by self-care
- Why it is important
- How to achieve self-care

### What you will need

- Large paper
- Marker pens
- Appropriate venue
- Winning ways to wellbeing handout
- Project pamphlets, such as the EHA produced one titled: "Care for yourself too"
- Any other pictures, diagrams, handouts you think would be useful

### ● First Activity – Warm Up

- Each person shares one highlight from the past week and one challenge.
- Do one of the warm up activities from previous weeks if time allows.
- Review last week's session.
- Ask the group to share how they used or tried different things they have learned from being in this group.

### Second Activity – What is Self-Care?

Divide the group into small groups or pairs.

Ask them to discuss:

- What is their understanding of self-care?
- Why do they think it is important to care or themselves as caregivers?
- What do they do to make sure that they look after themselves?

After they have had a discussion in small groups and pairs bring the group back to the wider group and review the discussion.

### Why is self-care important?

Self-care is important because before you can care for someone else you first need to care for yourself.

As a caregiver you need to be a role model. If you want your relative to care for themselves and take some responsibility for their own health, then you need to be a role model of this behaviour yourself.

Think about your caregiving role like a vehicle (car or motorbike). A vehicle needs fuel to in order to operate. If you run out of fuel, then you bike or car will not move. If you don't take care of your vehicle changing oil and changing tires taking it to the mechanic, then you will breakdown.

***As a caregiver you need to find what your fuel is and fill up regularly.***



**Get your fuel through the Five Winning Ways to Wellbeing<sup>4</sup>:**

**Give**

Your time,  
your words,  
your  
presence

**Be Active**

Do what you  
can, enjoy  
what you do,  
shift your  
mood

**Keep  
Learning**

Embrace new  
experiences,  
seize  
opportunities,  
surprise  
yourself

**Connect**

Talk, listen, be  
there, feel  
connected

**Take Notice**

Remember  
the simple  
things that  
give you joy

<sup>4</sup>Mental Health Association of New Zealand <https://www.mentalhealth.org.nz/>



### Other important things in order to take care of yourself as a caregiver

As a caregiver, you don't always have to always be a giver. You also need to receive help and support (take).

#### Take help from others

- Share the responsibility of your relative.
  - Are there other family members that you can share the responsibility with?
- Take responsibility for asking for help, as people may not know you need a break unless you tell them.
  - Let people help you if they offer.

#### Take a break

- Do things that bring you joy
  - Hobbies, church, prayer, sharing meals, shopping
- Spend time with other friends and family.
- Spoil yourself.
  - For example, haircut, beauty parlour etc.

#### Take care of your health

- Take healthy food/eat well
- Meditate
- Take Exercise
- Get what you need to feel energised and refreshed.
- Get appropriate amount of sleep.
- Prayer.

***Discuss as a group how each member is going to 'take' over the next week.***

#### Deep Breathing

One of the easiest ways to relieve tension is deep breathing.

- Lie on your back with a pillow under your head.
- Bend your knees (or put a pillow under them) to relax your stomach.
- Put one hand on your stomach, just below your rib cage.
- Slowly breathe in through your nose. Your stomach should feel like it's rising.
- Exhale slowly through your mouth, emptying your lungs completely and letting your stomach fall.

Repeat several times until you feel calm and relaxed. Practice daily. Once you are able to do this easily, you can practice this technique almost anywhere, at any time.

### Exercise

We can stop the harmful effects of stress, by doing some exercise every day.

- Exercise helps the body
- relaxing the muscles,
- helps release chemicals to the brain that make us feel good
- give us energy.
- It makes us strong and healthy.
- It takes away anxiety and tension.
- It makes us tired so that we sleep at night

What kind of exercise do you like?

- Decide what exercise you will do.
- Decide how often and how long you will exercise.

Start with small steps and build up slowly.

If you are reluctant to exercise, consider the reasons for this and find some solutions.

- Ask a family member or friend if they will support you and go for walk with you.

Discuss with the group what exercise you will do this week.

### Conclusion

- Recap the session.
- Ask the group to get into pairs and discuss:
  - What is the most useful thing they have learned today?
  - Three things that they will do for themselves over the next week.
- Bring back to the larger group and ask them to share what they discussed in pairs.

### Homework:

Tell the group they are going to be asked next week how they allowed others to help and support them as part of their self-care over the next week.

## Module Nine: Being an Effective Caregiver and Review

### Aim of Module:

For participants to combine what they have learned so far in the group for the purpose of becoming an effective caregiver and to review all previous weeks.

### What you will need

- Large paper and marker pens
- Copy of Who, What Where Why and How exercise from session one
- An additional staff member to help record feedback

### First Activity – Warm Up

- Share one highlight from the past week and one challenge.
- Do one of the warm up activities from previous weeks if time allows.
- Review last week's session.
- Ask the group to share how they used or tried different things they have learned from being in this group.

### Second Activity – How to be an Effective Caregiver

- Introduce the activity by stating that you want the participants to think about putting everything they have learned together.
- The main idea is to get the caregivers talking and discussing the table below.
- This exercise is meant to bring all the knowledge that has been learnt over the coming weeks together into one exercise, so they can learn to be a more effective caregiver.

### Third Activity – Who, What Where Why and How Activity

This activity was completed on the first session. Please bring the record that you made at that session to this session. Then today:

- Show the participants what their brainstormed answers were.
- Discuss how their knowledge about their role as a caregiver has changed.
- Repeat the activity again. The point of doing this is to ascertain the extent to which participants have gained more knowledge, and in which areas.

**Table 5.** Being an Effective Caregiver

In Relation to...	Caregiver	Relative with Mental Illness
<b>Understanding</b>	<ul style="list-style-type: none"> <li>■ Your role as a caregiver</li> <li>■ What does it mean to be a caregiver?</li> </ul>	<ul style="list-style-type: none"> <li>■ What is a Mental Illness?</li> <li>■ Mental illness is not your relative's fault</li> </ul>
<b>Compassion</b>	<ul style="list-style-type: none"> <li>■ Be kind to yourself</li> <li>■ Congratulate yourself on the job that you do</li> </ul>	<p><b>4R's</b></p> <ul style="list-style-type: none"> <li>■ Reassure your relative</li> <li>■ Respond to feelings</li> <li>■ Recognize when their brain is unwell</li> <li>■ React with kindness, patience</li> </ul>
<b>Realistic Expectations</b>	<ul style="list-style-type: none"> <li>■ You can't do everything alone</li> <li>■ Know what you can do</li> <li>■ What you can't do</li> <li>■ Ask and accept help</li> <li>■ Use shaping, modelling and mirroring behavior strategies</li> </ul>	<ul style="list-style-type: none"> <li>■ Can participate in their own care.</li> <li>■ Do not treat them as helpless. Give them responsibilities and tasks around the home</li> <li>■ Give them some responsibility with their own health.</li> </ul>
<b>Get Support</b>	<ul style="list-style-type: none"> <li>■ Respite</li> <li>■ Take a break</li> <li>■ Friends and Family</li> <li>■ Share responsibility with others</li> <li>■ Community Workers/Group</li> </ul>	<ul style="list-style-type: none"> <li>■ Doctor</li> <li>■ Community organisations</li> <li>■ Alcoholics Anonymous, etc.</li> <li>■ Church</li> <li>■ Project staff</li> </ul>
<b>Recognise Concerns</b>	<ul style="list-style-type: none"> <li>■ Caregiver Burnout</li> <li>■ Stress</li> <li>■ Changes in weight and or sleeping</li> <li>■ Social isolation/withdrawing from others</li> <li>■ Alcohol consumption</li> </ul>	<ul style="list-style-type: none"> <li>■ Challenging Behaviour</li> <li>■ Stress</li> <li>■ Changes in weight and or sleeping</li> <li>■ Social isolation/withdrawing from others</li> </ul>
<b>Plan</b>	<ul style="list-style-type: none"> <li>■ Make your own care plan</li> <li>■ Look after your own health (Five Winning Ways to Wellbeing)</li> <li>■ Take regular breaks from your caregiving role</li> <li>■ Consider where you can get support and accept help</li> </ul>	<ul style="list-style-type: none"> <li>■ Care plan</li> <li>■ Five Winning Ways to Wellbeing</li> <li>■ A daily routine</li> </ul>

### Review of Course

Divide the group into pairs and ask them to discuss in their pairs the following questions.

1. What information in the module was of the most interest for the group?
2. Was there any other information that should have been included?
3. How relevant was the module to the needs of the caregivers? Circle one.

Very relevant.

Relevant.

Not relevant at all.

4. Name three things that were really good about the caregiver group.
5. Name three things that should be changed about the module?
6. Please provide any other comments and feedback about the group.

Bring the group back together as a large group and discuss the answers as a whole group.

### What is the future of the group?

Discuss as a group. Now that the modules have finished:

- Will you continue to meet as a group?
- Will you meet even if project staff cannot arrange it?
- Who will take responsibility for coordinating the group?

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HOSPITAL  
ASSOCIATION

808/92 DEEPALI BUILDING  
NEHRU PLACE, NEW DELHI - 110019  
[www.aha-health.org](http://www.aha-health.org)