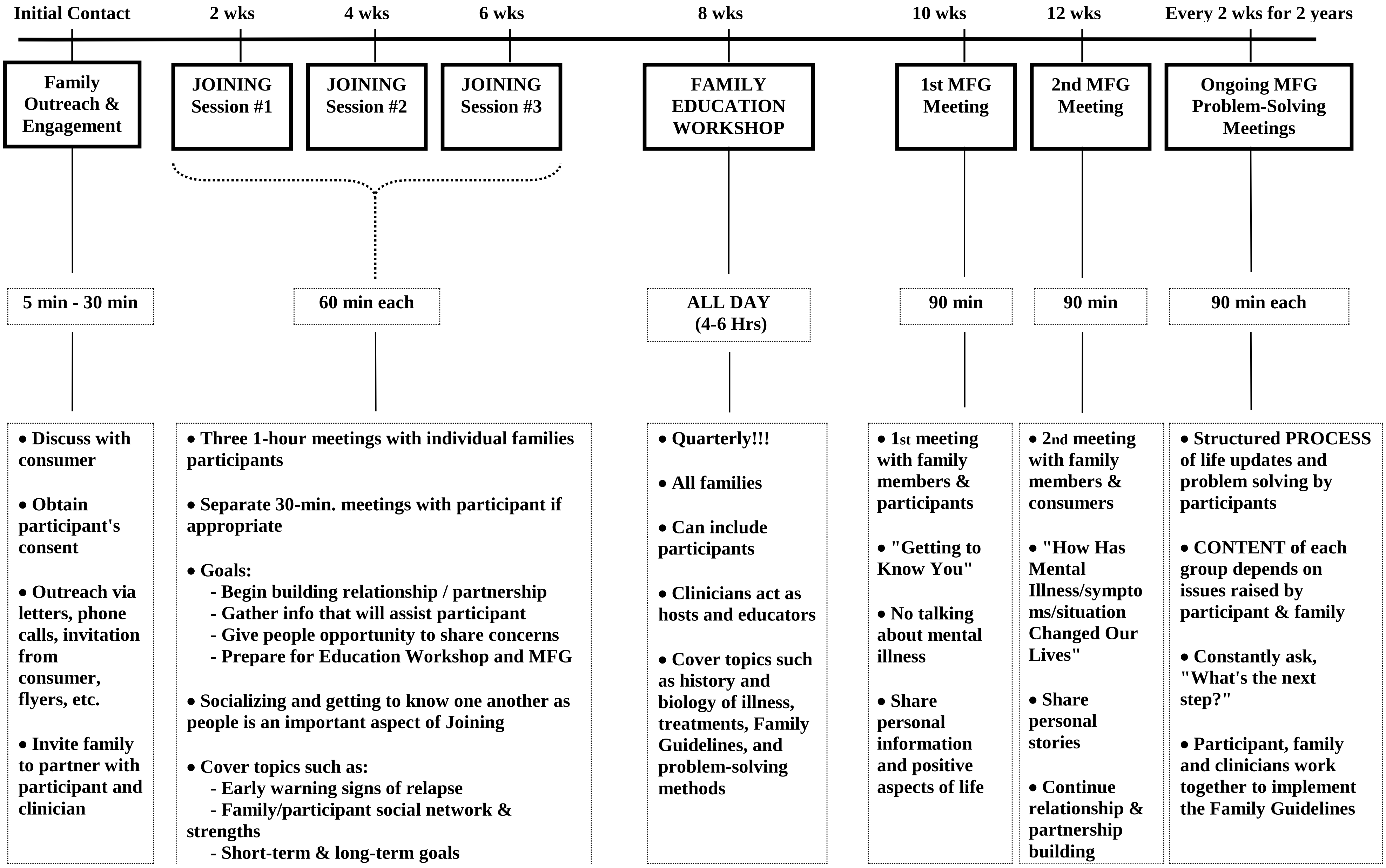
STAGES OF MULTIPLE FAMILY GROUP INTERVENTION



Initial Contact

Family Outreach & Engagement

5 min - 30 min

- **Discuss with consumer**
- **Obtain participant's consent**
- **Outreach via letters, phone calls, invitation from consumer, flyers, etc.**
- **Invite family to partner with participant and clinician**

2 wks — **JOINING Session #1**

4 wks — **JOINING Session #2**

6 wks — **JOINING Session #3**

60 min each

- **Three 1-hour meetings with individual families participants**
- **Separate 30-min. meetings with participant if appropriate**
- **Goals:**
  - **- Begin building relationship / partnership**
  - **- Gather info that will assist participant**
  - **- Give people opportunity to share concerns**
  - **- Prepare for Education Workshop and MFG**
- **Socializing and getting to know one another as people is an important aspect of Joining**
- **Cover topics such as:**
  - **- Early warning signs of relapse**
  - **- Family/participant social network & strengths**
  - **- Short-term & long-term goals**

8 wks

FAMILY EDUCATION WORKSHOP

ALL DAY (4-6 Hrs)

- **Quarterly!!!**
- **All families**
- **Can include participants**
- **Clinicians act as hosts and educators**
- **Cover topics such as history and biology of illness, treatments, Family Guidelines, and problem-solving methods**

10 wks

1st MFG Meeting

90 min

- **1st meeting with family members & participants**
- **"Getting to Know You"**
- **No talking about mental illness**
- **Share personal information and positive aspects of life**

12 wks

2nd MFG Meeting

90 min

- **2nd meeting with family members & consumers**
- **"How Has Mental Illness/symptoms/situation Changed Our Lives"**
- **Share personal stories**
- **Continue relationship & partnership building**

Every 2 wks for 2 years

Ongoing MFG Problem-Solving Meetings

90 min each

- **Structured PROCESS of life updates and problem solving by participants**
- **CONTENT of each group depends on issues raised by participant & family**
- **Constantly ask, "What's the next step?"**
- **Participant, family and clinicians work together to implement the Family Guidelines**

Competency Checklist for MFG Clinicians

Joining Sessions and Family Workshop

Multifamily Psycho-education Group Treatment

Clinicians ________________________ Date of Session ________________

Session ________________________ Date of Rating ________________

Circle One: **Videotape** **Audiotape** **Self monitor/Discussion**

Coding Key: ✓ = appropriately included **O** = optionally omitted **NA** = not applicable

Session 1

___ 1. The clinician socialized with the family for 15 minutes.

___ 2. The clinician presented self as a colleague and an advocate.

___ 3. The clinician shared relevant personal information about self.

___ 4. The consumer's history was reviewed.

___ 5. Early warning signs were identified.

___ 6. Symptoms of the illness were identified.

___ 7. The clinician explained the basic structure of the multifamily group experience and what the family can expect.

___ 8. Emphasis was placed on the concept that the family is not to blame.

___ 9. The clinician shared relevant information about the illness.

___ 10. The session ended with 5 minutes of socialization.

Session 2

___ 1. The clinician socialized with the family for 15 minutes.

___ 2. Exploration of the family's social network and resources occurred.

___ 3. The clinician identified family and consumer strengths.

___ 4. A genogram or sociogram was used in the session.

___ 5. The session ended with 5 minutes of socialization.

Session 3

___ 1. The clinician socialized with the family for 15 minutes.

___ 2. The clinician facilitated a discussion about the family and consumer’s short-term goals.

___ 3. The clinician facilitated a discussion about the family and consumer’s long-term goals.

___ 4. The clinician answered questions and provided information about the upcoming Family Workshop.

___ 5. Inquires were made regarding the family’s experience with groups and any concerns they may have about groups.

___ 6. The clinician asked the family for information regarding their past experiences with the mental health system care.

___ 7. A discussion occurred regarding the consumer and family’s response to living with and/or around the illness.

___ 8. The session ended with 5 minutes of socialization.

Multifamily Workshop

___ 1. The workshop was structured in a classroom atmosphere.

___ 2. Information about the nature, etiology, course and outcomes of schizophrenia was presented.

___ 3. Information about medications and current treatment was presented.

___ 4. Information about management of the illness was presented.

___ 5. Information regarding common reactions was presented.

___ 6. The Family Guidelines were presented.

___ 7. The problem solving method was presented.

___ 8. Specific questions were answered.

___ 9. Handouts were included and given to families.

___ 10. The clinicians’ manner was collegial, open and encouraged questions from family members.

___ 11. The clinicians acted as hosts, hostesses during the breaks assisting families in feeling comfortable.

MFG Workshop Planning Checklist

Workshop date ____________
Point person for workshop _______________

Identified group facilitators to provide joining sessions __________________

Client(s)	Staff to provide joining sessions

Family Speakers:

Client and/or family member to share	Staff to invite and confirm

2-3 months prior to the workshop date:

- ☐ Reserve Training Room space for the date of workshop and the Friday prior to it through DD support staff
- ☐ Identify which staff members are going to be at the workshop
- ☐ Identify clients and families who need to be invited
- ☐ Identify which MFG group each family is going into
- ☐ Group facilitators identify who is going to provide joining sessions for whom
- ☐ Invite identified clients and families to the workshop
- ☐ Invite identified clients and families to joining sessions

2 months prior to the workshop date

- ☐ Provide joining sessions to clients and families as described in the joining timelines with the goal of getting all three joining sessions in prior to the workshop date. If not possible, make sure all three joining sessions are done prior to the first MFG for the client and family so that they are fully prepared for it.
- ☐ Identify family speakers to share at workshop and invite them (usually at least 3, try and get different genders and ages)

1-2 months prior to the workshop date

- ☐ Review the Powerpoint slides and update any as necessary
- ☐ Identify who is going to plan the food and beverages for the workshop
    - Breakfast foods: yogurts, bagels & cream cheese, fruit and Coffee (Starbucks carrier)
    - Lunch foods: possibly catered from Hola! Or get bread, lunch meat and cheese plate, veggies for sandwiches, fresh veggie tray and/or green salad, chips, fruits from breakfast and non-alcoholic beverages (or some other foods that are easy to make)
    - Snacks: consider having nuts, chips, cookies, etc. for snacks throughout the day
        - Person(s) in charge of food & beverages: ____________________
    - Coffee: Starbucks coffee carrier
        - Person to pick up coffee __________________

    - Bags of ice to keep & ice chests needed
        - Person to pick up ice & get ice chests _____________
- ☐ Identify who is going to set up the computer and slideshow for workshop
        - Person in charge of the computer _________________

2 weeks prior to workshop date

- ☐ Identify one staff to get a final head count for number of participants and staff anticipated at the workshop & communicate the final number to the rest of the team at least one week prior to the workshop itself
        - FINAL HEAD COUNT: _____________
- ☐ Create an agenda of who is in charge of what part of the workshop
- ☐ Print out copies of the Powerpoint slides, agenda, and updated EASA contact list
- ☐ Prepare the folders with all handouts, articles, etc. (see document on shared drive in EASA MFG Workshop folder: How to organize the workshop folders)
        - Person putting together the folders: ________________
- ☐ Remind team what time they need to be at the office for set-up (usually at 8AM)

1 week prior to workshop date

- ☐ Make sure there are enough plates, napkins, utensils, cups for cold and hot water in the supply cabinets (if not, ask person getting food to pick up needed items when shopping at Costco)
- ☐ Gather blank name tags and sharpies
- ☐ Gather ink pens for people to take notes
- ☐ Confirm who is going to set up computer and slideshow for workshop
        - Person in charge of the computer _______________
- ☐ Remind team of what time they need to be there on Saturday morning to set up & ask if anyone is available to set up the room on Friday afternoon

1-2 days prior to workshop

- ☐ Food & Beverage person pick up food, beverages and any other needs for the food part of the day

Day of workshop

- ☐ Coffee person to pick up coffee carrier at Starbucks
- ☐ Ice person to pick up 2 bags of ice for ice chests
- ☐ Computer person sets up slideshow
- ☐ Team arrives to finalize any set up needs for the room, food and beverages, etc.
- ☐ All team members participate in the workshop, outreach to participants during breaks and lunch, and eat lunch with everyone
- ☐ Collect receipts for expenses and put in envelope to go to supervisor and put in supervisor's inbox
- ☐ Have fun!

Family Guidelines

1. **Go slow -** *things will get better in their own time.*
2. **Keep it cool -** *tone down disagreements and enthusiasm.*
3. **Give each other space -** *time out is important for everyone.*
4. **Set limits** - *few good rules keep things clear.*
5. **Ignore what you cannot change** - *let some things slide, but DON'T ignore violence.*
6. **Keep it simple** - s*ay what you have to say in clear, calm, positive terms.*
7. **Follow your recovery plan –** attend appointments, t*ake only medications that are prescribed and take them only as prescribed.*
8. **Carry on business as usual** - *re-establish family routines as quickly as possible and reconnect with family and friends.*
9. **No street drugs or alcohol** - *they make symptoms worse.*
10. **Pick up on early signs** - o*bserve changes then consult with your clinician.*
11. **Solve problems step by step –** *make changes gradually …work on one thing at a time.*
12. **Lower expectations temporarily** - *don't make unrealistic comparisons, e.g., compare this month to last month rather than this year to last year.*

Hướng Dẫn Gia Đình

1. **Chậm lại-** *mọi thứ sẽ tốt hơn trong thời gian riêng của nó.*

2. **Giữ bình tỉnh -** *đừng lớn tiếng khi bất đồng ý kiến và hãy hăng hái.*

3. **Cho nhau một khoảng cách –** *quan trọng cho mỗi người phải cho nhau một khoảng cách.*

4. **Đặt giới hạn** – *đặt những quy tắc để giữ cho mọi thứ được* rõ ràng.

5. **Đừng để ý những gì mình không thay đổi được-** *có vài thứ mình có thể bỏ qua, nhưng ĐỪNG bỏ qua sự đối sử bạo hành.*

6. **Giữ thật đơn giãn** – *nói những gì mình phải nói bằng những lời rõ ràng, bình tỉnh và cương quyết.*

7. **Theo kế hoạch phục hồi của bạn** – *tham dự các buổi hẹn, chỉ uống thuốc của bác sĩ cho toa và uống theo như toa.*

8. **Vẫn giữ công việc hằng ngày như bình thường** - *củng cố lại các sinh hoạt gia đình càng sớm càng tốt và kết nối lại với gia đình và bạn bè.*

9. **Đừng dùng ma túy hay rượu** - *những thứ này làm cho các triệu chứng tệ hơn.*

10. **Biết được những dấu hiệu sớm** – *quan sát những thay đổi sau đó tham khảo ý kiến bác sĩ của bạn.*

11. **Giải quyết các vấn đề từng bước một –** *thay đổi từ từ ...giải quyết các vấn đề từng một lúc mà thôi.*

12. **Giảm kỳ vọng xuống tạm thời -** *đừng có những so sánh không thực tế, thí dụ như so sánh tháng này với tháng trước thay vì* so sánh *năm này với năm trước.*

EASA FAMILY GUIDELINES

1. *Believe in your power* to affect the outcome: you can!

2. One step at a time.

3. Consider using medication to protect your future, if the doctor recommends it.

4. *Reduce stresses* and responsibilities for a while.

5. Use the *symptoms as indicators*.

6. Anticipate life stresses.

7. Keep it calm.

8. Give each other space.

9. Set a few simple limits.

10. Ignore what you can’t change.

11. Keep it simple.

12. Carry on business as usual.

13. Solve problems step by step.

14. Keep a *balanced life* and balanced perspective.

15. Limit alcohol and avoid street drugs.

16. Explain your circumstances to your closest friends and relatives and *ask* them *for help* and to stand by you.

17. *Don’t move abruptly* or far away until stability returns.

18. Attend the multi-family groups.

19. *Follow* the recovery *plan*.

20*. KEEP HOPE ALIVE!*

LINEAMIENTOS PARA LAS FAMILIAS DE EASA

1. *Crea en el poder que usted tiene* para cambiar los resultados: ¡usted puede lograrlo!

2. Un paso a la vez.

3. Considere utilizar los medicamentos para proteger su futuro si su médico así lo recomienda.

4. *Reduzca el estrés* y las responsabilidades durante algún tiempo.

5. Utilice los *síntomas como indicadores*.

6. Anticipe las situaciones estresantes de la vida.

7. Manténgase tranquilo.

8. Los miembros de la familia deben darse un poco de espacio entre sí.

9. Establezca algunos límites sencillos.

10. Ignore todo aquello que no pueda cambiar.

11. No complique las cosas.

12. Continúe con sus actividades de siempre.

13. Resuelva los problemas paso a paso.

14. Mantenga una *vida equilibrada* y una perspectiva balanceada.

15. Evite el consumo del alcohol y las drogas callejeras.

16. Explique sus circunstancias a sus parientes y amigos más cercanos y *pídales su ayuda* y su apoyo.

17. *No se mude abruptamente* ni se aleje demasiado hasta que regrese la estabilidad.

18. Asista a los grupos multi-familiares.

19. *Siga* el *plan* de recuperación.

20*. ¡MANTENGA VIVA LA ESPERANZA!*

1st and 2nd MFG Groups

1st MFG Group	2nd MFG Group
“Getting to know you”	“How mental illness/situation has changed our lives” “What brought you as a family to EASA”
15 minutes chat/ socializing Co-facilitators model behavior Share personal information and positive aspects of people’s lives (no talk about illness) Introductions are culturally normative Begin to develop trust and understanding	15 minutes chat/ socializing Co-facilitators model behavior Personal stories of impact of mental illness/symptoms are shared Continue relationship and partnership building

Structure of Sessions – Multifamily groups (MFGs)

1. Socializing with families and consumers		15 m.
2. A Go-around, reviewing— a) The week's events b) Relevant biosocial information c) Applicable guidelines		20 m.
3. Selection of a single problem		5 m.
4. Formal Problem-solving a) Problem definition b) Generation of possible solutions c) Weighing pros and cons of each d) Selection of preferred solution e) Delineation of tasks and implementation		45 m.
Socializing with families and consumers		5 m.
	Total:	**90 m.**

PMFG Problem Solving Session
Tips for Setting up the board

Name:	Going Well ☺ "What is going well, relative to the guidelines?"	Could be better ☹
Mike	Brief description of what is going well	Brief description of what could be better. Start thinking/writing in terms of a problem definition here.
Jan		
Anita		
Betty		
Myron		
Amy		
Member		
Member		
Member		
Member		
Member		

(The grid lines are not necessary for the board.) Use this information to (briefly) summarize everyone's go-round information at end of the go round. This will recognize and validate their participation. Leaders then review the "could be better" and triage, (offer immediate help when appropriate), and pick a problem based upon PMFG Hierarchy. Leaders have a transparent discussion (even disagreement) when choosing. After selecting the problem, they turn to family and invite them to do their problem solving. Then move on to the problem definition segment.

PMFG Problem Solving Session
Tips for Setting up the board
Problem solving section

Problem Definition: What can John (consumer-family member) do about (about, with, to cope with, in response to-<u>this word/phrase is the "operator"</u>") his (his, her, their, our,-Pronoun) fear of having a drug relapse (this is a description of the problem and/or description of the emotional response to the "problem").

	Solutions	Pros and cons
1		++++ - - -
2		+++++ - -
3		++ - -
4		
6		
7		
8		
9		

10 (You can manage the group's time by reducing or adding to the total number of solutions you generate. If things are going smoothly and you have lots of time, add some solutions. Pressed for time because of a long go-round, tell the group you will brainstorm for fewer (quality) solutions. If pressed for time later in the group, run through only two or three of the Pros and Cons for each brainstorming solution.

Unless otherwise indicated, it is good to begin the problem definition with, the action words "what can Myron do". Making a numbered list helps to focus people and leaders on generating solutions. This also becomes the group record of problem-solutions-and rating of the pros and cons. The consumer takes this sheet home with the action plan included in the bottom section. (Complete sheet to follow) The action is a complete separate section led by the leaders wherein they work with the client to identify what they choose to do (or not do) and the steps they might take to accomplish this by next meeting. This is: What will you do? When might you do it? Will you need help, and if you do need help, who will help you and when?

Multifamily Group
Problem Solving Worksheet

Date:____________________

Step 1: What is The problem?

Talk about the problem, listen carefully, ask questions, get everyone's opinion…Then write down exactly what the problem is.

____

____

Step 2: List 10 Possible Solutions

All ideas, even unlikely ones. Encourage participation of all group members.

1.____

2.____

3.____

4.____

5.____

6.____

7.____

8.____

9.____

10.____

Step 3: Discuss Pros and Cons of Each Solution.

Step 4: Choose the Best Solution or Combination of Solutions *(circle above).*

Step 5: Plan How to Carry Out the Best Solution. (What, who, when, how?)

____

____

Family Psychoeducation
Individual Progress Note

Name:_____________________________ ID#____________________ Date:____________________

Name of significant other(s) involved in session:____

Check item if this activity occurred to a meaningful degree, whether successful and /or effective or not. Please use on progress note per session.

JOINING SESSION

- ☐ Socializing with family and patient
- ☐ Exploration of precipitating factors to illness
- ☐ Review of prodromal symptoms/signs
- ☐ Family's reaction to the illness
- ☐ Family's coping strategies, successful and Unsuccessful
- ☐ Social network and other support resources
- ☐ Preparation for multifamily group
- ☐ Goals for the treatment and likely length of Treatment
- ☐ Provide information about illness and course of recovery time

MULTIFAMILY GROUP ONE
"Getting to Know One Another"

- ☐ Socializing
- ☐ Each individual introduces him, or herself Emphasizing strengths and point of pride
- ☐ Participants do not dwell on illness nor criticize others

MULTIFAMILY GROUP TWO
"Living With a Mental Illness"

- ☐ Socializing
- ☐ Each individual describes how the illness has affected him or her
- ☐ Group leaders end session on hopeful theme, emphasizing solving the problems created by the illness and working toward recovery

MULTIFAMILY GROUP OR SINGLE-FAMILY SESSIONS

- ☐ Socializing with families and patients
  - ☐ A Go-Around, reviewing:
  - ☐ Status of employment
  - ☐ Recent life events
    - ☐ Substance use
    - ☐ Applicable guidelines
  - ☐ Selection of a single problem
  - ☐ Formal problem-solving
    - ☐ Problem definition
    - ☐ Generation of possible solutions
  - ☐ Addressing disadvantages and advantages of each
  - ☐Selection of preferred solution
    - ☐ Delineation of tasks and implementation

Clinician Signature______________________________________ Date_________________

Draft 2002: Family Psychoeducation Fidelity Scale

When a Brother or Sister Develops Psychosis: What Siblings Need

√Information
1 What’s happening? How can I help? What can I expect?
2 The amount and type of information desired will vary by person

√Someone to talk to who will listen and not make things worse
3 Usually resist talking openly with parents

√Minimization of trauma
1 Need to have a place to process this soon after it happens

√Honesty and reassurance

√Normal family activities and special occasions

√Support for normal developmental needs
2 Safety
3 Individuation
4 Educational/vocational
5 Extracurricular/fun
6 Spiritual, emotional
  - Special attention to grief, trauma

7 Physical
8 Family time

√Parents to take care of themselves and be OK

√Support for setting limits or figuring out how to relate

√Impact is affected by:
1 Birth order, age of siblings
2 Personalities and prior relationship with ill sibling
3 Nature of sibling’s symptoms
4 Whether and how long they live in the home
5 Course of sibling’s illness

√Common reactions
1 Becoming the “well” child; being there for everyone else
2 Withdrawal
3 Anger/ getting into trouble
4 Fearfulness about developing illness themselves

√Long-Term Effects: Can affect spirituality, relationship choices, role in family, career choices; without assistance, extended grief process is common.

What to Do If a Brother or Sister Develops Psychosis

- ✓ *Know you are not alone*. 1-3% of the population develops a psychosis, and chances are at least one or two of your friends share this experience.

- ✓ *Seek out someone you trust* to talk to. Keep looking until you find someone.

- ✓ Know this is a *no-fault* illness. Your sibling does not choose to experience it.

- ✓ Maintain a *supportive, positive attitude*. Recovery is a one step at a time, and can be slow. Sometimes people aren't ready. Communicate to them what you value about them. Be honest.

- ✓ *Stay safe*, physically and emotionally. Let your parents and your sibling know if you do not feel safe, and insist on healthy boundaries.

- ✓ *Focus on your own strengths and goals*. Let your experience with the illness inform, not dominate your life.

- ✓ Seek counseling, especially if you have experienced traumatic situations. *Don't be ashamed to ask for help*. Many people whose siblings experience psychosis end up making different choices in career and relationships because of that experience. Be aware that these experiences are affecting you.

- ✓ Stay in touch with a *strong support network*- friends, mentors, youth groups, extracurricular activities, etc.

- ✓ *Don't try to act as a parent* or to solve the problem. You cannot. Just be yourself.

- ✓ *Don't feel guilty* for your own joy or for your own success. Celebrate those, and encourage your sibling to take his or her own risks.

- ✓ *Don't judge* your sibling's progress by where you think he/she should be. Psychosis makes normal things very difficult, and can stop a person in their tracks. People who choose to actively manage their condition can do very well in life, but may take a little time. Honor your sibling for the challenges he/she is facing, his/her persistence and courage, and the real strengths and talents you value.

- ✓ *Educate yourself* about the illness and how it affects you and your family members.

Raising Teens

Massachusetts Institute of Technology
The MIT Work-Life Center

Ten Tasks of Adolescent Development

In order to help parents influence healthy adolescent growth, the Raising Teens Project identified 10 critical developmental tasks that teenagers need to undertake to make a successful transition to adulthood:

1. **Adjust to sexually maturing bodies and feelings**
   Teens are faced with adjusting to growing bodies and newly acquired sexual characteristics. They must learn to manage sexual feelings and to engage in healthy sexual behaviors. This task includes establishing a sexual identity and developing the skills for romantic relationships.

2. **Develop and apply abstract thinking skills**
   Teens typically undergo profound changes in their way of thinking during adolescence, allowing them more effectively to understand and coordinate abstract ideas. They begin to think about possibilities, try out hypotheses, plan ahead, think about thinking, and construct philosophies.

3. **Develop and apply a new perspective on human relationships**
   Teens typically acquire a powerful new ability to understand human relationships. Having learned to "put themselves in another person's shoes," they begin to take into account both their perspective and another person's at the same time. They learn to use this new ability to resolve problems and conflicts in relationships.

4. **Develop and apply new coping skills in areas such as decision making, problem solving, and conflict resolution**
   Teens begin to acquire new abilities to think about and plan for the future, to engage in more sophisticated strategies for decision-making, problem solving, and conflict resolution, and to moderate their risk-taking to serve goals rather than jeopardize them.

5. **Identify meaningful moral standards, values, and belief systems**
   Teens typically develop a more complex understanding of moral behavior and underlying principles of justice and caring for others. They question beliefs from childhood and adopt more personally meaningful values, religious views, and belief systems to guide their decisions and behavior.

During the teen years, adolescents grow in size, sexual maturity, emotional development, and thinking capacity. The developmental changes during adolescence rival those of infancy and early childhood. Research indicates that the human brain does not reach full maturity until at least the mid 20s.

Most milestones occur gradually, with frustrating starts and stops along the way. Each task depends on others to be fully accomplished, and all are part of underlying developmental forces propelling adolescents toward maturity.

In addition, many researchers see human development as a lifelong process, with parents developing alongside their adolescents.

Continued on next page

Ten Tasks of Adolescent Development

Continued from previous page

6. **Understand and express more complex emotional experiences**
   Teens shift toward an ability to identify and communicate more complex emotions, to understand the emotions of others in more sophisticated ways, and to think about emotions in abstract ways.

7. **Form friendships that are mutually close and supportive**
   Teens develop peer relationships that play powerful roles in providing support and connection in their lives. They tend to shift from friendships based largely on shared interests and activities to those based on sharing ideas and feelings, mutual trust, and understanding.

8. **Establish key aspects of identity**
   Forming an identity is a lifelong process, but crucial aspects of identity are typically forged during adolescence, including developing an identity that reflects a sense of individuality as well as connection to valued people and groups. Another part of this task is developing a positive identity around gender, physical attributes, sexuality, ethnicity, and (if appropriate) having been adopted—as well as sensitivity to the diversity of groups that make up American society.

9. **Meet the demands of increasingly mature roles and responsibilities**
   Teens gradually take on the roles that will be expected of them in adulthood. They learn to acquire the skills and manage the multiple demands that allow them to move into the labor market as well as meet expectations regarding commitment to family, community, and citizenship.

10. **Renegotiate relationships with adults in parenting roles**
    Although the task of adolescence has sometimes been described as "separating" from parents and other caregivers, it is more widely seen now as adults and teens working together to negotiate a change in the relationship that balances autonomy and ongoing connection. The emphasis on each depends in part on the family's ethnic background.

For more information about brain changes in adolescence, visit the Young Adult Development Project website: **http://hrweb.mit.edu/worklife/raising-teens**

Raising Teens

Massachusetts Institute of Technology
The MIT Work-Life Center

The Raising Teens Project identified five significant ways in which parents can foster healthy adolescent development—the Five Basics of Parenting Adolescents:

- **Love and Connect**
  Offer support and acceptance while affirming the teen's increasing maturity.
- **Monitor and Observe**
  Let teens know you are paying attention.
- **Guide and Limit**
  Uphold clear boundaries while encouraging increased competence.
- **Model and Consult**
  Provide continual support for decision making, teaching by example and ongoing dialogue.
- **Provide and Advocate**
  Provide a supportive home environment and a network of caring adults.

Researchers agree that the essential role of parents really changes very little from childhood to adolescence. What can and must change are the strategies for carrying out this role.

Research in no way suggests that "one size fits all." Rather, these parenting strategies offer starting points from which to adapt ideas that fit the characteristics of each family, culture, circumstance, and teenager.

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http://hrweb.mit.edu/worklife/raising-teens

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Path to Recovery

"there's definitely life after psychosis. You definitely can overcome it, if you just work hard enough and have the right support systems. It can be just the beginning of a new and enriched life."

Quote from an Oregon EASA graduate

What matters to you?

- Relationships with friends and family
- Making a difference in the world
- Having fun
- Being able to support myself
- Having a home
- Getting through school
- Having a good job

Psychosis directly affects all of these things, but you can be successful if you have the right information, attitude and support. The following steps are based on the learning of others who have experienced psychosis.

Each person's symptoms and recovery process are unique. However, there is much to learn from the experience of others. EASA attempts to summarize these experiences in order to increase the likelihood that each young person will succeed.

1) Recognizing a Problem

The following checklist can help you decide whether you may be experiencing a condition needing attention. In some situations, others who are close to you may notice changes you don't notice. If you've experienced any of the following for more than a few days, or if someone close to you has noticed these things, it is worth having a good medical checkup:

Changes in your perceptions

- Things look, sound or feel different than they did before
  Examples: More intense, boundaries blurring, hard to figure out what things are for
- Seeing or hearing things that other people don't
- Other changes that are hard to describe, such as changes to perception of distance or time

Changes in your moods

- Angry or depressed disproportionate to your circumstances

- Extreme highs and lows
- Fear of others hurting you

Changes in your thoughts

- Obsessing about certain ideas
- Racing thoughts
- Developing unusual beliefs

Changes in your sleep

- Not sleeping, sleeping all the time, or sleep reversed from normal pattern

Harder to do things

- Having trouble with memory or concentration
- Not doing as well in school or work
- Having conflicts in relationships with family or friends
- Withdrawing socially from other people
- Not as interested in basic self care: eating, staying clean, etc.

Others expressing concern that there's something wrong

Physical changes

- Changes in appetite, or other signs of physical illness

Quite often people with psychosis do not recognize that something has changed. It is often others in their lives who notice significant changes and encourage the person to get help. Most people who experience psychosis have difficulty accepting the need to manage it as a medical condition. Why?

- No matter what the medical condition, most people go through a period where they don't accept the need to manage it. It is part of the normal process of adapting.
- Because psychosis affects the brain directly, the person's perceived experiences seem immediate and real.
- Psychosis can also interfere with a person's ability to "test reality"- to critically analyze whether their own conclusions are correct.

- Many people have inaccurate or old ideas about what "psychosis" and similar terms mean. They may have "internalized stigma"- in other words, they are unable to accept the labels because of all the negative assumptions they have about those words.

Most people define the problem in their own way, using their own words. Some common language people use to describe their experiences:

- "Special sensitivity"
- "Unable to filter information"
- "Special abilities"
- Difficulty concentrating or sleeping

Some of the symptoms are harder for a person to recognize than others, although others around them may be noticing the changes.

Symptoms which are EASIER for people to recognize include:

- Difficulty with concentration
- Difficulty with sleep
- Obvious visual or auditory hallucinations, although people often have trouble knowing how to interpret these
- Difficulty with day-to-day functioning at school, work and home

Symptoms which are HARDER for people to recognize include:

- Changes to their thought process and how they are drawing conclusions about information
- Changes in motivation, behavior and mood

Some people have trouble differentiating psychosis from religious or cultural beliefs. A skilled counselor can help sort out the difference.

2) Getting Support

- Family and friends are one of the most important things in helping us to regain wellness
- Ask someone you trust to help you through this process.
- Your family and friends will need support and education, just like you will.
- Encourage them to get educated at the same time that you're educating yourself.
- Give permission to doctors and counselors you work with to talk to the people you have chosen as supporters.
- Stay involved with other people- social interaction is important for recovery!

3) Staying Safe

- If you are upset, antsy or very energized, channel this into safe activities. Use words, not actions to express strong feelings.
- Know who to call. Carry their phone numbers with you and put it in several places around the house. (Crisis Contacts)
- Have a back-up plan: what happens if the first person doesn't answer?
- Anticipate what could happen and have a plan. Talk to a counselor about possible major stressors and things you should watch for. Identify things you can do to avoid a crisis.
- Include other people in your plan: family, friends, trusted professionals. Ask them to play a role, and make sure they have a copy of the plan.
- Consider completing an advanced directive. This is a legal document which explains what you do and don't want to have happen in case of a psychiatric emergency. Information about advanced directives can be found at the Disability Rights Oregon website: www.disabilityrightsoregon.org
- For more information on crisis planning, see the crisis resources section (Crisis Contacts)

4) Keeping an Open Mind

- When you have found a doctor or counselor you trust, share what are you experiencing and how you are interpreting it.
- Pay attention if other people are expressing concern about changes in your behavior or thinking. Often, other people are better able to observe changes in us than we are
- Listen to the interpretations of others you trust, and work together to come to a shared understanding
- Stay focused on the things that have always mattered to you- school, work, hobbies, relationships, etc.

5) Keeping Hope!

- Look for opportunities to meet other people who have been through the same thing and who are doing well
- Remember: you are not an illness! don't accept negative assumptions about labels such as "psychosis", "schizophrenia" or "bipolar disorder".
- Be around people who are positive toward you and avoid being around people who act negatively toward you.
- Give yourself time to recover and give yourself credit for what you are able to do.

6) Take responsibility

- You are responsible for your own life! Others can offer support, but no one else can do this for you

- Use the resources and supports available to you.
- Listen, listen, listen.
- Ask questions and share your concerns.
- Write things down: keep track of what works, what doesn't work and why.
- Look for your own answers and share them with others.
- Set long-term and short-term goals.
- Take it one small step at a time. It's OK to rely on others.
- Most people need significant support from others during recovery, and sometimes need others to make decisions temporarily.
- Let others know what you need and want.

7) Know your rights

No matter how ill a person is, they have certain rights outlined by law. The Disability Rights Oregon's web site (www.disabilityrightsoregon.org) has an excellent description of those rights. Your rights include:

- to make informed decisions about your own treatment;
- to reasonable accommodations (adaptations) at work and school (for a good resource see: https://cpr.bu.edu/) and in your housing situation;
- to receive financial and health care assistance if you have a disabling condition which prevents you from working;
- to choose your own treatment;
- if your illness endangers your safety or that of others, you still have numerous rights, including due process and to be treated with respect;
- Family members may also have the right to take time off from work through the Family Medical Leave Act.

8) Choose the right treatment

Once an assessment is complete, the doctor and counselor will be able to provide preliminary information about your diagnosis and what type of treatment is likely to be helpful. One of EASA's goals is to support you in making your own informed treatment decisions.

Treatment for psychosis normally includes the following:

- Ongoing fine-tuning of the assessment and diagnosis
- Medications prescribed by a psychiatrist or psychiatric nurse
- Education about your condition, recovery process, rights and resources
- Counseling by a mental health professional to:
    - help you adapt to the situation
    - learn to manage the symptoms
    - clarify and support progress toward your goals

    - keep your self esteem
- Participation in groups with other people who have experienced a similar condition
- Assistance with financial, housing, relationships, school, work, and other areas which may have been affected by the psychosis
- Support for your family and friends

You and your team will develop a plan which identifies the goals most important to you, and how they will support you in getting there. Normally there is a written "treatment plan", which identifies what goals you are working, who is doing what, and when. If you don't know what's in your treatment plan, you should ask for a copy. The treatment plan should be based on your own goals.

9) Medications

Most people who experience ongoing psychosis need to take medicine in order to manage the symptoms. Antipsychotic medications help restore the brain's chemical balance. There are two general types of antipsychotics: Novel or atypical, and typical antipsychotics. "Typical" antipsychotic medications are the older medicines. They tend to have more movement-related side effects and are used less commonly than the "atypical" antipsychotics for that reason. Generally the prescriber will try to find a dose which is low enough to avoid significant side effects and high enough to affect the symptoms. It is very important to talk to the prescriber about any side effects or if you are thinking about reducing or changing medicines.

IMPORTANT NOTE: It may take as long as 8 weeks to see the full effect of an antipsychotic medication. It is important to continue the medicine long enough to determine whether it is effective. Also, sometimes people will experience more severe side effects during the first two weeks, with the side effects going away soon thereafter. The prescriber may also prescribe an anti-anxiety agent, a mood stabilizer, or an anti-depressant.

Be sure to talk to the doctor about:

- How you will you know this medicine is working (what symptoms are you targeting)
- When during the day you should take the medicine
- What to do if you miss a dose
- How long it will take before you can expect to see improvement
- What side effects should you watch for, and what should you do if you experience them?

10) Adapting

Psychosis is a no-fault illness. Successful adaptation goes through a series of stages, which may be repeated and which may overlap.

Psychosis brings many losses, and most people who experience it go through a grief process to heal from those losses. Predictable stages of grief include:

- Denial, a time when you may be unwilling to acknowledge that there is anything wrong. It is common for people to withdraw from others during this stage.

  Remember: don't accept negative assumptions or stigma. You are a unique, talented person with a lot to contribute. Whatever challenges or inconveniences you face, your contribution will be that much greater.

- Anger- at yourself, others, the system. Talk about your feelings with someone you trust. Remember you are responsible for your own behavior. Choose not to blame.

- Bargaining- Thinking if I just do this, things will be back to the way they were. If I just take my medicine, if I just pray, if I just work hard enough. The truth is, psychosis changes people's lives. With successful adaptation, the changes can be positive.

- Depression- It's OK and natural to experience depression as part of the healing process from psychosis. It's part of the process. It can be helpful to meet other people who have experienced psychosis who are leading successful lives. This will help you hold onto hope for a positive future. Also, talk to your doctor and counselor about these feelings.

- Acceptance. Acceptance involves the acknowledgement that you are the person who has the "key to your own life." At this stage you begin to feel more compassion for others. It is the moment at which lasting recovery begins.

11) Educating yourself

Part of the process of moving forward is educating yourself about the things that affect you. That includes your specific medical condition/diagnosis and other things which relate to your specific goals. Your doctor and counselor will be a great source of information. You may also want to seek out a college counselor, vocational rehabilitation counselor, or others who have specific knowledge you need.

There are many excellent self-help resources, some of which are listed on this web site in the "links" section.

12) Setting goals and pacing yourself

Know where you want to go but take it one step at a time. Set small, specific short-term goals for yourself, then stay focused on them. Make changes gradually. Pat Risser, a long-time mental health advocate, uses the analogy of a ladder. You have been progressing through life for a long time, going from one rung to the other. When you experience psychosis, It is like falling off the ladder. It takes some time to recover, and when you start to feel better again you may have a tendency to want to jump right back to where you are. But if you do that, there's a good chance you will crash. You're more likely to be successful if you take it slowly, one step at a time, and eventually you will find your way back to where you were and move beyond. Plus, you will find that your new skills and experiences will be helpful to you in the future.

13) Preventing relapse

An important part of long-term recovery from psychosis is relapse planning. The more experience you have, the more sophisticated your self-awareness becomes, and the more proactive you become in managing your own health.

Some good news:

Most of the time, it is possible to detect and prevent relapse either before it occurs or at the early stages.

The strategies which are successful in preventing relapse for psychosis are similar to strategies which prevent a whole range of other acute illnesses.

The same strategies which prevent relapse also lead to being healthier in general.

Psychosis is cyclical:

Psychosis and other conditions such as mood disorders tend to be cyclical. This means they go through predictable stages:

- The "well" stage either before the onset, or when symptoms are in remission or under control
- A "prodromal" stage when you are seeing early warning signs which are progressively becoming more severe (more intense, more frequent and lasting longer)
- An "acute" stage when you experience the most obvious symptoms of psychosis- hallucinations, delusions and/or thought disorder
- Early recovery when acute symptoms have gotten better and you are beginning to stabilize
- Late recovery when you are getting back to a "well" state- you may still have some persistent symptoms, especially issues with memory and concentration, but they are manageable and not getting worse.
- This same pattern applies to many chronic illnesses.

Psychosis is affected by stressors:

Everyone is vulnerable to psychosis, but some people can develop it more easily than others. People who are more vulnerable to psychosis need to be aware that there are things which can reduce that vulnerability (increase resilience), and there are things they can do to make themselves more vulnerable, which we refer to as "triggers".

Some things that can make psychosis worse ("triggers"):

- Not sleeping
- Living in a very stressful environment
- Interacting with people who are very critical or negative toward you
- Making too many demanding changes at once (moving out on your own while starting a full-time job, etc.)
- Extreme social isolation
- Using street drugs or alcohol
- Using large quantities of caffeine
- Not eating or drinking well
- Not moving your body enough
- Anniversaries of traumatic events
- Not taking medicine as prescribed

Things that can make psychosis better:

- Regulating sleep so you keep balance
- Avoiding substances which haven't been prescribed
- Taking the proper dose of prescribed antipsychotic medicines
- Staying involved with a supportive social network
- Identifying your most important needs and making sure they're met
- Setting and following through on manageable goals
- Having regular contact with a team of supportive professionals
- Staying active physically and mentally
- Keeping good nutrition and water intake
- Regularly doing things you enjoy

An effective relapse plan includes the following information:

- Daily practices which will help you stay well
- Triggers which may make you more vulnerable to relapse, and what you will do to reduce their impact
- Early warning signs indicating that you may be heading toward a psychosis, and what you will do if they occur
- Late warning signs that indicate you are in an acute stage, and what you will do, what others will do, and any other preferences or concerns you have (for example, if you have to go to the hospital are there certain medicines that work for you and others you want to avoid; if you are in respite temporarily, who will take care of your plants and pets, etc.)

Relapse plans should be re-visited regularly to make sure they are meaningful to you and complete. Everyone involved in your support system should have their own copy, and it is helpful for the local crisis team to also have a copy.

- You also have the right to turn your relapse plan into an advance directive. An advanced directive is a legal document which describes what you want to have happen in case things reach an acute stage where you're no longer able to make good decisions for yourself. For more information, visit the Disability Rights Oregon's website at www.disabilityrightsoregon.org in the "Mental Health Law" section, under "Declaration for Mental Health Treatment".

How to put together a relapse plan

With people who know you well and your mental health counselor and/or doctor, write down the following information, based on your previous experience:

A. What do you do on a daily basis to help you stay well?

B. When you have had previous experiences with psychosis, what led up to them?

Were there noticeable triggers?

What changes did you or others notice before the relapse happened?

What changes were noticeable first, and how did they progress?

Each person has their own early warning signs. You can get a good idea of what those are for you by re-thinking what happened before previous acute episodes. Quite often, early symptoms may start to occur weeks or even months before a full relapse. Common early signs include:

Not sleeping

Growing confusion, depression, anxiety or irritability

Not coping with work or study

Avoiding social situations

Loss of energy or motivation

Feeling suspicious or paranoid

Unusual or bizarre beliefs

Hearing voices or seeing visions

Racing or obsessive thoughts

A significant reduction in ability to do ordinary things

When thinking about your early warning signs, be as specific as possible. Some other examples of unique early warning signs people have identified for themselves:

- Laughing frequently and out of context
- Taking baths more frequently
- Dreaming about spiders
- Painting on a larger canvas than usual
- Listening to specific music artists more often
- Beginning to think that other people are changing shapes

Next, think through what symptoms or changes you noticed in the later stages. Again, be as specific as possible.

C. In each stage, what did you do that seemed to help?

D. Think about your strengths and resources.

What resources are available to you (people, places, etc.)?

What have you done before that worked?

What helps you relax and feel better when you're stressed?

E. Now, think through how you will prevent and respond to symptoms:

What will you do on a day-to-day basis to help prevent unnecessary symptoms (stress management, balanced lifestyle, medicines, etc.)

How will you monitor symptoms?

Who else will help you monitor them?

What symptoms are you watching for?

What will you do if the symptoms occur?

Who will you call, when?

What will you do?

What do you WANT to happen if symptoms get worse (strategies that have worked before or that you think would work)

What do you NOT want to happen if symptoms get worse (strategies that have not been successful before- example: medicines which did not work well for you, bad experiences you don't want to repeat)

What's your back-up plan?

F. With your counselor, put your plan into a written format (preferably on computer disk so you can change it easily).

Periodically, look at the plan and think about what's working or not working, and what might need to be changed.

Make sure that everyone who plays a part in the plan has reviewed it and agreed to their role.

Personal Relapse Avoidance Plan (A form for you to print)

14) Coping with persistent symptoms

While medicine and lifestyle strategies usually greatly reduce or eliminate symptoms, symptoms may persist:

You may have certain low-level persistent symptoms even while you're on medicine;

You may experience flare-ups due to stress, illnesses or other factors;

In some cases medicine doesn't help specific symptoms.

It is important to know that the severity of your symptoms is not the most important predictor of your success. Motivation and previous experience are just as important. If you really want something in your life, you can learn to cope with symptoms in order to get there.

Symptoms are just that: they are symptoms. They do not prevent you from acting on your goals. How you react to symptoms is more important. For example, if you hear voices that tell you to do things, and you do what they say, it will probably get you in trouble in life. If you learn to ignore the voices and use your judgement, you will do much better.

There are specific skills which are helpful in learning how to cope with symptoms:

Relaxation skills. Symptoms are usually very stress-related, and if you learn to manage stress better, you will also learn to manage symptoms. Some things you can do to help manage stress:

Exercise regularly

Focus your energy on things you enjoy and that come easily

Engage in routine calm activity, such as reading, gardening, taking a bath

Keep a regular sleep schedule of at least 8 hours per day

Spend time with people who like you and have a positive attitude

Observation skills. By observing your own emotional state and symptoms, you can change how you react. Also, symptoms are often triggered by specific environmental phenomena (such as turning on a television or having an argument with someone), may occur at particular times of day, or may result from pushing yourself too far (working too many hours, staying up too late, dealing with too much environmental stimulation). You may be able to detect a pattern and develop new strategies for avoiding or reducing symptoms.

Reality testing. Psychosis is a disorder which interferes with information processing, so it is important to double-check perceptions with others. By exploring alternative explanations for things you experience which are distressing, you can learn to reduce the likelihood of drawing inaccurate conclusions. You can also learn to do this by yourself.

"Handholds to reality". Esso Leete refers to "handholds to reality;" things which you can do that keep you tuned into the world around you. Examples of this are regular conversation with others, using a calendar, having a daily routine and structure, having goals you're working on, and doing reality testing with another trusted person.

Keeping a peaceful, orderly environment. It's important to have a safe, comfortable place to live, preferably with others who you trust and who care about you. Environments which are very chaotic or where there is a lot of emotional expression may make symptoms worse.

Learning from others. There are many good self-help resources where people share what's worked for them in coping with specific symptoms. You may want to experiment with some of their ideas to see whether they work for you. In particular, Mary Ellen Copeland (Wellness Toolbox), Esso Leete (article: "How I Perceive and Manage My Illness)," and Fred Frese (http://www.fredfrese.com) have all identified specific strategies which have been helpful to them and others.

15) Giving back to others

Many people find that when they have begun to achieve a solid recovery, an important part of their recovery process is to give to others. There are many ways to do this- to share your experiences in person or writing, to co-facilitate a support group, to volunteer your time in the community, or just to be a little kinder to people you know. Look for opportunities to give back by giving feedback, public speaking, mentoring, being on oversight groups and committees, and helping in designing and developing the early psychosis intervention program.

Believe in your power to affect the outcome: you can!

Validating beliefs can build self-confidence ('I can do this!'), and support focus on the here-and-now moment so that you can take next steps in the recovery/healing process.

One step at a time

Stresses and demands are taken seriously and steps toward healing/recovery are paced to keep stress below the threshold for symptom exacerbation, reduce risks for relapse and promote success across life domains/goals/aspirations.

Consider using medications to protect your future, if the doctor recommends it

Low dose medications, a standard practice of care in early psychosis treatment programs, have been found in research studies to be very helpful in reducing symptoms in individuals with schizophrenia spectrum and other psychotic disorders. Medication has been found to be an effective form of treatment for reducing symptoms in individuals with bipolar disorder.

Reduce stresses and responsibility for a while

This helps individuals and family members slow down which can reduce stress in order to focus on the healing process and build strength for next steps in healing/recovery. Remember this is often temporary and will not be a pace that you follow forever!

Use the symptoms as indicators

Learn individual's unique early warning signs and take agreed upon action steps to have the best chance at reducing the likelihood early signs and symptoms will get worse.

Referring to and following the Relapse Prevention Plan let's the individual's preferences and understanding of what does and does not help direct family members and support people's involvement in preventing a relapse. Having a plan in place can greatly reduce stressful situations from becoming more stressful!

Anticipate life stresses

Keep it calm

Supports environmental accommodations by family and support people to avoid too much sensory stimulation and promote calm atmosphere

> (Examples: reduce background noise, light levels in room, avoid multiple conversations at once)

Helps negative symptoms stabilize over time.

Give each other space

Allows for time-outs and a time and place to for family members and young people to withdraw from others without criticism
Okay to continue to invite to activities and allows for people to decline offer while staying connected.

Set a few simple limits

Allows for everyone to know what the expectations are in home, daily routine, substance use, etc. Clear expectations can lower stress.

Ignore what you can't change

Identify and avoid stressful topics. Encourages family members to adapt and accommodate for symptoms that are beyond their control, like stopping someone else's delusional thought; and stay in conversation.
(Examples: change the subject, move away from getting stuck on ideas that reflect a person's delusional thoughts)

DO NOT IGNORE violence
DO NOT IGNORE hints or threats of suicide

Keep it simple

To help with information processing difficulties, conversations can be:
shorter, less complex, and sensitized to stressful topics unique to the individual.
This approach will help protect and buffer complexities that the individual negotiates in their everyday life and the world.

Avoid guessing what other people and thinking and support each person to speak on their own behalf, in the least stressful way possible.

Carry on business as usual

Supports family members to continue or reestablish family routines. This can increase predictability in typical daily life activities, allow for family member participation in household responsibilities, and reduce stress that comes from disruption of typical routines.

Solve problems step-by step

Reduces stress from tackling too many problems at once.

Supports your ability to prioritize steps you and your supporters need to take in order to succeed at problem-solving.

Accommodates cognitive differences and encourages everyone's voice and perspective get included in problem-solving.

Keep a balanced life and balanced perspective

Limit alcohol and avoid street drugs

Alcohol and street drugs can make symptoms worse and get in the way of the effectiveness of prescribed medications.

It helps to make decisions about alcohol and street drug use that fit personal and family lifestyle choices values as well as an individual's risks for symptom relapse.

Explain your circumstances to your closest friends and relatives and ask them for help and to stand by you

Don't move abruptly or far away until stability returns

Attend the multi-family (or single family) problem-solving meetings.

Follow the recovery plan

Keep HOPE alive!

Ref" W.R. Mcfarlane 2010 PIER Training Instittue ppt

Family Involvement in Treatment and Supporting Recovery

With a few exceptions, families should be in regular communication with healthcare professionals. This means that family members should:

- provide information in the initial assessment process, because most of the time family members are aware of changes that the person is unable to observe or report;
- meet periodically with doctors and counselors;
- be aware of the person's diagnosis, and be involved in developing the treatment plan;
- play a role in treatment, such as helping to remind the person about taking medicine, monitoring and reporting symptoms, and supporting the person in their goals.

A few pointers:

- If the person is unwilling to sign a release of information to have the professionals talk to family members, family members can still give information to the professionals about their observations. Also, professionals should be willing to talk in general terms about diagnosis, treatment and problem solving, and families should still seek out educational resources.
- Some professionals are less willing to meet with families than others. It is important to find a professional who understands the importance of the family role is, and who wants to talk with you.
- Try to be concise and specific in your communication with professionals. They may miss your most important points if you provide too much information at a time.
- When communicating with professionals, it is helpful to write things down in concise, specific bullets.
- When advocating, it is helpful to choose the one thing that is most important and focus on that, rather than trying to advocate for several things at once.
- It's helpful to review written records and make corrections where you see errors.

A few tips in supporting the treatment process:

- In the early stages, psychosis affects all aspects of a person's ability to care for himself or herself. It may be difficult to get out of bed, to prepare meals, to shower, to remember things, to read, to get organized and motivated to do anything. This is part of the illness. Be patient, prioritize, and encourage progress one step at a time.
- It is OK to help your loved one. Use the following question about whether your involvement is helping or hindering: Am I helping my loved one to do more or less? If the answer is less, you may want to reconsider your approach. But remember, in the beginning everything they do will probably be a major struggle for them.

- Most people with psychosis have difficulty with short-term memory. In the early stages, it is particularly important to pay attention to whether people are getting their medicine as prescribed.
- Where the person is at developmentally may affect what role you can play. If they are rebelling against you, you may need to work more closely with other friends, family members and professionals to let others take on caregiving roles.
- Maintain a positive, hopeful attitude. While it is a long process, recovery is likely and "Slow and steady wins the race."
- Continue to involve your loved one socially with friends and family.
- Educate other friends and family members about the illness and what to expect.

Advocating for change:

If you are unhappy with any aspect of the services you are receiving, it is important to talk directly to the person who is most involved, whether It's your counselor, doctor, or someone else. You can also call a supervisor, and if you're part of OnTrak, you can call the Program Coordinator. Try to be specific about what you need or would want. You always have the right to change case manager or doctor, although there may be limitations of availability within agencies.

Each agency has a published complaint/grievance process to help resolve problems as they arise. For state-funded services, you have the right to appeal a grievance to the state level.

Almost everything that has been achieved in the mental health system has happened because of advocacy by people who were affected. It is important for decision makers at all levels to hear the stories of the people the "system" is supposed to serve; otherwise, it cannot possibly be responsive or helpful.

There are many opportunities for advocacy. NAMI offers excellent conferences and training, and advocates at local, state and national levels. Many local NAMI groups meet regularly in an "official" capacity with important local decision makers, and often being an "official representative", or having an official position by a NAMI group can be very persuasive to local decision makers. Local mental health programs and other public organizations have governance and advisory boards you can join. All publicly funded managed care programs are mandated to involve families and people in recovery in committees and governance. There are many ways to get involved!

The OnTrak program is one way to learn more and meet others who have an interest in fostering a proactive, positive, responsive community for people with psychosis. Systematic early intervention for psychosis is extraordinarily rare in the United States, and the services offered by OnTrak are not available everywhere. Thus, families commonly must cope without the type of professional support they need. As the voices of young people in recovery and their families are heard more often throughout the U.S., that reality will change.

Impact of Psychosis on Family Members

Grief. Psychosis can have a tremendous impact on all family members. Almost universally, psychosis is accompanied by a grief process which affects everyone. The stages of the grief process include shock/denial, learning to cope, and acceptance. Individuals at different stages of grief need different things.

Family conflict. Family members are often at different places in the grief process, which may cause conflict. As families continue to deal with psychosis, they may go through the grief process many times. This is normal. However, it is also important to pay attention to how family members are affected by the stress and grief associated by this illness, and not to hesitate to get additional counseling. Psychosis often causes a great strain on marriages and family relationships, since individuals may reach very different conclusions about how to handle the situation. Patience and communication skills become critically important.

Since psychosis is often preceded by early, or "prodromal" symptoms, families often observe changes for an extended period before they begin to understand what's happening. Prodromal (early) symptoms such as sleep disorder, social withdrawal and behavior changes are often mistaken for drug use, intentional conduct problems or laziness. In fact, as people deal with some of the early changes to memory, concentration and thought process, they may turn to substance use as a way of coping.

Developmental impact. Symptoms of psychosis have a direct effect on development. One of the goals of early psychosis intervention is to minimize that impact so that the person will move on with life in a positive way. Since psychosis usually affects people starting between ages 15 and 25, some of the key developmental tasks can be directly impacted:

- Experimenting with and forming an independent identity
- Individuating and separating from parents
- Learning independent living skills
- Living independently
- Finishing school

- Entering the work force and identifying a career path
- Establishing adult peer relationships
- Sexuality
- Starting a family

If these developmental tasks are interrupted, the person will need to return to them later before they'll be able to progress developmentally. Also, each member of the family who is directly affected by psychosis will likely be affected developmentally. Parents who are preparing to send their child out into the world experience a return to dependency and a need to provide more direction. Siblings often develop a fear of developing psychosis themselves and may make different choices in relationships because of their need to cope with confusion, grief and loss.

What is psychosis?

"Psychosis" is a broad term that covers many different symptoms and experiences.

Common symptoms include:

- Hallucinations (seeing, hearing feeling or tasting things that other people don't)
- Feeling overwhelmed by sensory information (lights seem too bright, noises too loud)
- Difficulty filtering stimulation from the environment
- Delusions (false personal beliefs based on incorrect inferences about reality which are inconsistent with culture and previous beliefs, and which are firmly sustained in spite of evidence or proof to the contrary)
- Confused thinking or speech
- Difficulty doing ordinary things (often includes problems with memory, attention, putting thoughts together)

Who experiences psychosis?

Anyone can develop psychosis. Many people see or hear things that others don't, or have ideas that are unusual. Psychosis is only a problem when it is causing you or someone close to you significant distress or harm.

It affects 3 in 100 people, and usually occurs for the first time between the ages of 15 and 30. Men often develop psychosis 5 to 10 years younger than women. It can be caused by a variety of medical illnesses, sleep deprivation, severe stress or trauma, drug reactions, genetic predisposition, and other factors.

Common Early Signs of Psychosis

Some of the most common signs of psychosis include:

- A sudden loss of interest in things that the person used to find enjoyable
- Inability to do the things that the person could do before (e.g., a person who normally loves math suddenly can't do it anymore)
- Social withdrawal and isolating from friends and family
- Dramatic changes in sleep pattern
- Statements or behavior that are bizarre and inconsistent with what's going on around them

Emergence of Symptoms

Psychotic disorders rarely emerge suddenly. Most often, the symptoms evolve and become gradually worse over a period of months or even years. Early symptoms often include cognitive and sensory changes which can cause significant disability before the illness becomes acute and is finally diagnosed. Identifying and responding appropriately to the condition early can help to get the person and their family support.

1. Reduced Performance

- Trouble reading or understanding complex sentences
- Trouble speaking or understanding what others are saying
- Becoming easily confused or lost
- Trouble in sports or other activities that used to be easy (Example: can't dribble basketball or pass to team members)
- Attendance problems related to sleep or fearfulness

2. Behavior Changes

- Extreme fear for no apparent reason
- Uncharacteristic and bizarre actions or statements
- New, bizarre beliefs
- Incoherent or bizarre writing
- Extreme social withdrawal
- Decline in appearance and hygiene
- Dramatic changes in sleeping or eating

3. Perceptual Changes

- Fear that others are trying to hurt them
- Heightened sensitivity to sights, sounds, smells or touch
- Making statements like "my brain is playing tricks on me"
- Hearing voices or other sounds that others don't
- Reporting visual changes (colors more intense, faces distorted, lines turned wavy)
- Feeling like someone else is putting thoughts into their brain or that others are reading their thoughts

Earlier on, symptoms may be intermittent and the person often recognizes that something is wrong. As psychosis progresses, people lose their ability to distinguish symptoms from reality, and it becomes more difficult to have a conversation. For example, a person who has auditory hallucinations will hear voices which sound to them as loud and real and a person standing right next to them, even though others don't hear it. A person whose psychosis has progressed may not believe that other people don't hear the same voices and may not be able to integrate new information from others into their thinking.

Psychosis may also result from, or accompany, a mood disorder such as major depression or bipolar disorder (in which there are dramatic swings in energy level, sleep patterns, mood and behavior).

Example: A Concerning Change

Jonathan really liked two things: fixing computers and hanging out with his friends. So when he suddenly stopped doing both, it came as a big shock. His best friend came to visit and found him staring off into the distance.

"Have you been fixing that laptop?" she asked.

"No." Jonathan's face didn't seem to show any emotion. His tone was flat.

"Are you feeling down? Depressed?"

Jonathan shrugged. "I don't know. I can't seem to focus on anything anymore. My computer screen hurts my eyes."

As time passed, Jonathan's teachers and parents started noticing differences too. He stopped doing his homework and would skip class. Then, his friends noticed that he was posting unusual statements on Facebook.

"Aliens are out to get me and they're talking through the TV," he wrote. "I'm scared. I don't know what to do."

Stories like these are not uncommon for people experiencing psychosis for the first time. It can be very concerning for both the individual and their family, friends, and allies. But there is hope.

Many young people experience psychosis and still realize their hopes and goals. It is important that they receive support from their families, friends, allies, and mental health. Please use the "Get Help Now" button to find a support network near you.

Symptoms of Psychosis

Psychosis is generally defined in terms of "positive" symptoms. "Positive" symptoms are those symptoms which manifest outwardly, including hallucinations, delusions and speech disorder (also referred to as thought disorder). Many people who experience psychosis also experience additional types of symptoms: mood symptoms (relating to moods and energy levels), abnormal movements and behaviors, "negative" symptoms (things that aren't there now that that used to be), and cognitive symptoms (having to do with information processing). Below is a more detailed description of each type of symptom. Below is a more detailed description of each type of symptom.

Insight:

It's important to understand that people usually are aware of some symptoms but not others.

This is in part because of the nature of the symptoms themselves. Think of the analogy of an optical illusion. Your brain perceives and interprets information, but the information is interpreted incorrectly because of the way your brain constructs the information. Only when someone points out the error and when you use tools such as a ruler to "reality test" your perception do you recognize that it is an optical illusion. Psychosis is very similar. The brain perceives and interprets information erroneously, but the person is unaware that this is happening. Certain symptoms such as distressing hallucinations, paranoia and anxiety are often perceived as problematic to the person. However, most people do not recognize them as medical symptoms, and many of the other symptoms are recognized primarily by other people. For this reason it is critical for close family members and others who are known and trusted by the individual to be involved in the assessment and ongoing treatment process. Part of the process of treatment is helping the person to learn to distinguish and differentiate symptomatic perceptions from normal perceptions.

Positive Symptoms:

Hallucinations: Seeing, hearing or feeling things that others don't. This can range from an intense experience of color, blurring or distortion of visual images, to hearing sounds or voices with no apparent source, and seeing or feeling objects or phenomena which others do not.

Delusions: False beliefs based on incorrect inferences about reality, inconsistent with culture, experience and previous beliefs, and held with conviction despite evidence to the contrary. Delusions can be caused by a variety of information processing dysfunctions, involving sensory input, memory, attention, and interpretation. Some common delusions:

Delusions of reference: Belief that day-to-day events or experiences refer directly to you; for example, that the people on the TV set are talking directly to you, that street signs, license plates, or behaviors (such as coughing) carry communications specifically aimed at you.

Delusions of grandeur: Belief that you are able to do things which are beyond normal capacity, such as fly or act as royalty.

Persecutory delusions: Belief that others are trying to hurt you, for example, by poisoning you or through a conspiracy to cause you harm.

Nihilistic delusions: Belief that you or others do not exist.

Thought broadcasting: Belief that your thoughts can be read by others.

Thought insertion: Belief that others are placing thoughts in your head.

Thought withdrawal: Belief that one's thoughts are being extracted from the mind.

Thought control: Belief that feelings, thoughts and actions are not one's own, experienced as being imposed by an external source.

Speech/thought disorder:

These are symptoms related to the person's ability to communicate. The person may experience changes to their use of speech and the way they construct sentences. Examples include:

Frequent changes of ideas, making little sense to others (circumstantiality, tangentiality, derailment, looseness of association, flight of ideas)

Incoherent jumble of words (word salad)

Choosing words based on sound, such as rhyming or punning (clang associations)

Making up words which mean something only to the speaker (neologism)

Echoing others' words (echolalia)

Abnormal movements and behaviors:

A person may develop odd behaviors, movements or mannerisms, or may become unable to move on their own (catatonia, waxy flexibility or posturing)

Negative symptoms:

The following common symptoms are similar to some of the cognitive symptoms, but are commonly classified as "negative" symptoms (i.e. something taken away, versus "positive" symptoms, where something new is occurring):

Lack of facial expression (affective flattening) or inability , to detect facial cues from others;

Absence or restriction of speech (alogia);

Difficulty initiating goal-directed behavior (avolition/anhedonia)

Inability to experience pleasure and/or maintain social contacts (anhedonia/asociality)

Inability to maintain mental focus (attentional impairment)

Mood symptoms:

Depression: Predominant mood is depressed and there is a loss of interest or pleasure in nearly all activities for at least 2 weeks. Depression in its severe forms can cause psychosis. Depression can also be an early warning sign of psychosis for people who have schizophrenia.

Suicidal thoughts. It is important to know that many people who experience psychosis also experience suicidal thoughts, and the risk of suicide is significantly greater than for people who do not experience psychosis.

Mania: Period of time in which a person's mood is elevated or irritable, there is a lack of restraint in behavior, and highs in energy, requiring little or no sleep. Severe mania can cause psychosis, or a person can have both mania symptoms and psychosis symptoms distinctly from each other.

Anxiety. Extreme anxiety is common with psychosis.

Cognitive symptoms:

Most people who experience psychosis also experiences difficulty with memory, attention, and organization of thoughts. These symptoms may improve but often do not disappear completely with treatment for psychosis.

More information about psychosis:
For a comprehensive and highly useful text, we recommend Psychosis: A Wellness Approach, by Mary Moller. This text can be ordered at http://www.psychiatricwellness.com

Causes of Psychosis

Psychosis is a condition which affects the brain's ability to process information. Psychosis can affect sensory perception, ability to organize information, and ability to express information. There are many causes. Everyone has the potential to develop psychosis, if they don't sleep for multiple days in a row, if they take certain drugs or develop certain medical conditions, or if they experience extremely severe and prolonged stress. Psychosis has a strong genetic component. Individuals whose family members have experienced psychosis will be at greater risk for developing it themselves. Some people with a particularly great vulnerability to developing psychosis have to manage it as an ongoing condition.

The following illnesses or conditions, among others, can cause symptoms of psychosis.

- Sleep deprivation (psychosis should remit after the person sleeps)-
  See www.sleepnet.com for more info on sleep disorders.

- Drug use (psychosis usually goes away within 72 hours, although our experience with methamphetamine is that it may take longer). See http://www.psychosissucks.ca/epi/index.cfm?action=substanceuse
- Cushing's syndrome
- Adverse reactions to prescribed medications, such as steroids
- Thyroid and parathyroid disorders
- Cerebral sarcoidosis
- Systemic lupus erythematosus
- Very advanced cases of AIDS (some of the medicines can also cause psychosis)
- Sex chromosome abnormalities http://turners.nichd.nih.gov/
- Demyelinating diseases such as multiple sclerosis and Schilder's disease, especially if they involve the temporal lobes
  http://www.nmss.org/
- Encephalitic diseases
  http://www.ninds.nih.gov/health_and_medical/disorders/encmenin_doc.htm
- Wilson's disease
  http://www.wilsonsdisease.org/
- Huntington's disease
  http://www.ninds.nih.gov/health_and_medical/disorders/huntington.htm
- Friedreich's ataxia
  http://www.ninds.nih.gov/health_and_medical/pubs/friedreich_ataxia.htm
- Vitamin B12 deficiency
  http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3404901/
- Subarachnoid hemorrhage
- Cerebral tumors
- Head injury
- Temporal lobe epilepsy
  http://www.epilepsy.com/information/professionals/about-epilepsy-seizures/psychiatric-and-behavioral-aspects/psychiatric-2
- Mood disorders: Clinical depression or bipolar disorder
- Schizophrenia
  www.schizophrenia.com

What families need	**What family psychoeducation provides**
Safety for themselves and their loved one	Individual focus on what the person and family needs; assistance with boundary setting; problem solving and support
Listening and being heard	Listening and context
Empathy and non-judgment	Empathy and non-judgment
Understanding of what's happening	Detailed information about symptoms and what we know about psychosis
A team to help them	Information about the role of clinical team members; broadened support
Guidance about how to be helpful	Family guidelines about how to help
Coaching about how to communicate with a person	Specific communication techniques; opportunities for practice
A way to work through conflict	Better understanding of why conflicts emerge and way to work them through
Information about treatment choices	Information about treatment options
Other people who understand	Expanded social network and ideas
Hope	Examples of recovery, reframing, positive and attainable way to work through difficulties
Effective treatment	Evidence-based practice which addresses family needs and improves recovery
Patience	Information about what to expect; process where they can see ongoing progress
A place to turn; reciprocal support	Ideas you would not come up with; opportunities to contribute to others
To work through fear and grief	Context and support about normal reactions and recovery, hope
To play their normal developmental role (parent of young adult, sibling, etc.)	Understanding of the impact on family members; spreads responsibility
Coping and resilience	Encouragement and valuing of strengths and positive coping strategies

What young people need from families	**What family psychoeducation provides**
Belief in their ability	Understanding that the person is trying
Acceptance and encouragement	Awareness of symptoms, process of recovery and how to help
Empathy and non-judgment	Understanding of what the person is going through and the slow nature of recovery
To be heard and make decisions	A space to be heard and power to make decisions
Concrete help (a place to live, finances, transportation)	Reduces conflict and encourages modifications in expectations
Space	Encourages families to give each other space
Responsibilities and respect	Encouragement to keep challenging the person as they are ready
Reassurance	Better understanding of what psychosis is like
Ways to work through conflict	Specific and simple techniques for working through conflict and coming to agreement