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## 60 Tips for Helping People who have Schizophrenia

- **Tips for Handling a crisis**
- **Tips for Communicating**
- **Tips for Avoiding Relapses**
- **Setting Boundaries**
- **How to behave around someone with a brain disease like schizophrenia**
- **Tips for Coping with Having a Family Member who has Schizophrenia**

By Rex Dickens or the NAMI Sibling and Adult Children Network.

If you have a family member with neurobiological disorder ("NBD", formerly known as mental illness), remember these points:

1. You **cannot cure** a mental disorder for a family member.
2. Despite your efforts, **symptoms may get worse**, or may improve.
3. If you **feel much resentment**, you are giving too much.
4. It is **as hard** for the individual to accept the disorder **as it is** for other family members.
5. Acceptance of the disorder by all concerned may be helpful, but not necessary.
6. A **delusion will not go away by reasoning** and therefore needs no discussion.
7. You may learn something about yourself as you learn about a family member's mental disorder.
8. Separate the person from the disorder. **Love the person**, even if you hate the disorder.
9. Separate medication side effects from the disorder/person.
10. It is not OK for you to be neglected. You have needs &

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wants too.

11. Your chances of getting mental illness as a sibling or adult child of someone with NBD are 10-14%. If you are older than 30, they are negligible for schizophrenia.

12. Your children's chances are approximately 2-4%, compared to the general population of 1%.

13. The illness of a family member is **nothing to be ashamed of**. Reality is that you may encounter discrimination from an apprehensive public.

14. **No one is to blame.**

15. Don't forget your sense of humor.

16. It may be necessary to renegotiate your emotional relationship.

17. It may be necessary to revise your expectations.

18. Success for each individual may be different.

19. **Acknowledge the remarkable courage** your family member may show dealing with a mental disorder.

20. Your family member is **entitled to his own life journey**, as you are.

21. Survival-oriented response is often to shut down your emotional life. Resist this.

22. Inability to talk about feelings may leave you stuck or frozen.

23. **The family relationships may be in disarray** in the confusion around the mental disorder.

24. Generally, those closest in sibling order and gender become emotionally enmeshed, while those further out become estranged.

25. Grief issues for siblings are about what you had and lost. For adult children the issues are about what you never had.

26. After denial, sadness, and anger comes acceptance. The addition of understanding yields compassion.

27. The mental illnesses, like other diseases, are a part of the varied fabric of life.

28. Shed neurotic suffering and embrace real suffering.

29. The mental illnesses are not on a continuum with mental health. **Mental illness is a biological brain disease.**

30. **It is absurd to believe you may correct a physical illness such as diabetes, the schizophrenias, or manic-depression with talk**, although addressing social complications may be helpful.

31. **Symptoms may change over time while the underlying disorder remains.**

32. The disorder **may be periodic**, with times of improvement and deterioration, independent of your hopes or actions.

33. You should **request the diagnosis and its explanation from professionals.**

34. Schizophrenia may be a class of disorders rather than a single disorder.

35. Identical diagnoses does not mean identical causes, courses, or symptoms.

36. Strange behavior is symptom of the disorder. **Don't take it personally.**

37. You have a right to assure your personal safety.

38. Don't shoulder the whole responsibility for your mentally disordered relative.

39. You are not a paid professional case worker. **Work with them about your concerns.**

Maintain your role as the sibling, child, or parent of the individual. **Don't change your role.**

40. Mental health professionals, family members, & the disordered all have ups and downs when dealing with a mental disorder.

41. Forgive yourself and others for mistakes made.

42. Mental health professionals have varied degrees of competence.

43. If you can't care for yourself, you can't care for another.

44. You may eventually forgive your member for having MI.

45. The needs of the ill person do not necessarily always come first.

46. It is important to have boundaries and set clear limits.

47. Most modern researchers favor a genetic, biochemical (perhaps interuterine), or viral basis. Each individual case may be one, a combination, or none of the above.

**Genetic predisposition may result from a varied single gene or a combination.**

48. **Learn more about mental disorders.** Read some of our recommended books like *Surviving Schizophrenia: A Family Manual* by Dr. E. Fuller Torrey and *Overcoming Depression* by Dr. Demitris Papolos and J. Papolos.

49. From *Surviving Schizophrenia*: "Schizophrenia randomly selects personality types, and families should remember that persons who were lazy, manipulative, or narcissistic before they got sick are likely to remain so as schizophrenic." And, "As a general rule, I believe that most persons with schizophrenia do better living somewhere other than home. If a person does live at home, two things are essential--solitude and structure." And, "In general, treat the ill family member with dignity as a person, albeit with a brain disease." And, "Make communication brief, concise, clear and unambiguous."

50. It may be therapeutic to you to help others if you cannot help your family member.

51. Recognizing that a person has limited capabilities should not mean that you expect nothing of them.

**52. Don't be afraid to ask your family member if he is thinking about hurting himself.**

**A suicide rate of 10% is based on it happening to real people. Your own relative could be one. Discuss it to avoid it.**

53. Mental disorders affect more than the afflicted.

54. Your conflicted relationship may spill over into your relationships with others. You may unconsciously reenact the conflicted relationship.

55. It is natural to experience a cauldron of emotions such as grief, guilt, fear, anger, sadness, hurt, confusion, etc. You, not the ill member, are responsible for your own feelings.

56. Eventually you may see the silver lining in the storm clouds: increased awareness, sensitivity, receptivity, compassion, maturity and become less judgmental, self-centered.

57. Allow family members to maintain denial of the illness if they need it. Seek out others whom you can talk to.

58. **You are not alone.** Sharing your thoughts and feelings with others in a support group is helpful and enlightening for many.

59. The mental disorder of a family member is an emotional trauma for you. You pay a price if you do not receive support and help.

60. Support AMI/FAMI and the search for a cure!

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## TIPS FOR HANDLING A CRISIS

(The following is from the Washington State AMI via AMI of Hamilton County, Ohio. It has suggestions on how to handle a family member who is becoming psychotic. Note that each person is an individual and these suggestions may not apply to all. )

There are some actions that can diminish or avoid disaster. You need to reverse any escalation of the psychotic symptoms and provide immediate protection and support to the MI person. Remember: **Things always go better if you speak softly and in simple sentences.**

Seldom will a person suddenly lose total control of thoughts, feelings, and behavior. **Warning signs include: sleeplessness, ritualistic preoccupation with certain activities, suspiciousness, unpredictable outbursts, etc.** During these early stages a full blow crisis can sometimes be averted. If the person has ceased taking medications, encourage a visit to the physician. The more psychotic the patient, the less likely you'll succeed. Trust your feelings. If you are frightened, take immediate action.

Your task is to help the patient regain control. **Do nothing to agitate the scene.** The patient is probably terrified by the subjective experience of loss of control over thoughts and feelings. The "voices" may be giving life-threatening commands; messages may be coming from the light fixtures; the room may be filled with poisonous fumes; snakes may be crawling on the window. Accept the fact that the patient is in an "altered reality state" and may "act out" the hallucination, e.g. shatter the window to destroy the snakes. It is imperative that you remain calm. If you are alone, call someone to stay with you until professional help arrives.

The patient may have to be hospitalized. Try to convince him or her to go voluntarily; **avoid patronizing or authoritative statements.** If necessary, take steps to start the involuntary treatment process. If indicated, call the police but instruct them not to brandish any weapons. Explain that your relative or friend is mentally ill and that you have called them for help.

**DON'T THREATEN**-This may be interpreted as a power play and increase

fear or prompt assaultive behavior.

**DON'T SHOUT**-If the person isn't listening, other "voices" are probably interfering.

**DON'T CRITICIZE**-It will make matters worse; it can't make things better.

**DON'T SQUABBLE WITH OTHER FAMILY MEMBERS** over "best strategies" or allocations of blame. This is no time to prove a point.

**DON'T BAIT THE PATIENT**-Into acting out wild threats; the consequences could be tragic.

**DON'T STAND OVER THE PATIENT**-If he is seated. Instead, seat yourself

### **AVOID CONTINUOUS EYE CONTACT OR TOUCHING**

**COMPLY WITH REQUESTS**-That are not endangering or beyond reason. This gives the patient the opportunity to feel somewhat "In control."

**DON'T BLOCK THE DOORWAY**-But keep yourself between the patient and an exit.

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Following are some more Tips for Coping with someone who has a neurobiological disorder. Some are from AMI/APRIL, some are by Dr. Gil Tunnell at Bellevue, and some are from Marion Burns at Kings Park.

1. **Go Slow.** Recovery takes time. Rest is important. Things will get better in their own time.
2. **Less Stimulation.** Keep it cool. Enthusiasm is normal. Tone it down! Disagreement is normal. Tone it down, too!
3. **Give 'em space.** Time out is important for everyone. It's okay to offer. It's okay to refuse.
4. **Set limits and have structure. Everyone needs to know what the rules are.** A few good rules keep things calmer.
5. **Let some things slide.** Ignore what you can't change. Don't ignore violence!
6. **Keep it simple.** Say what you have to say clearly, calmly and positively.
7. **See that Dr's. orders are followed.** Take medications as they are prescribed. Take only medication that is prescribed.
8. **Socialize and carry on business as usual.** Reestablish family routines quickly as possible. Stay in touch with family and friends. Take vacations.

9. **No street drugs or alcohol.** They make symptoms worse.

10. Pick up on early signs of relapse. **Note changes such as inappropriate fear, annoyance, etc.**

11. **Solve problems step by step.** Make changes gradually. Work on one thing at a time.

12. **Lower expectations, temporarily.** Use a personal yardstick. Compare this month to last month rather than last year or next year. month rather than last year or next year.

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### How to Avoid Relapses

1. Provide a structured, **supportive, tolerant, low stress environment.** Set clear expectations of behavior and review them carefully. Give your relative clearly defined tasks, but keep expectations moderate. Learn to expect and tolerate some degree of deviant behavior. Have a set routine in the household with regular hours for meals, tasks, and other activities.

2. **Keep home atmosphere as calm as possible.** Each family member should speak for themselves and be allowed to finish what they are saying. Don't "mind-read" what another family member is thinking or feeling. Allow each family member to handle their own communication with another family member. Don't ask a brother to tell a sister. Do it yourself. Remind each other of that.

3. **Do not get emotionally overinvolved with your relative.** Give them psychological and physical space (ex. let them go to their room or take a walk). Keep criticism and over enthusiastic praise to a minimum. Don't be overly intrusive of your ill relative's thoughts or feelings, like saying, "you wouldn't like that kind of work" or "you really don't like so and so". Expect that they may rest or pace a lot, and indulge in unusual but harmless behavior. Allow this. Adopt an attitude of "Benign indifference" and a decreased focus on the details of the ill person's behavior.

4. **Put limits on hostile or bizarre behavior.** Often deviant behavior or delusional verbalizations will decrease if he is told, in a non-emotional way, that it is not appropriate. If your relative has paranoid ideas (like they feel people are out to hurt them) don't argue them out of it. Just sympathize, saying it must be upsetting to feel like that. Be very clear but calm about the consequences of continuing with disruptive, hostile, or aggressive behavior.

5. Help in providing stimulation and treatment. **Recognize changes in the person that signal they are ready for more independence, or need more help if doing less well.** Inform doctors, therapists, etc. of changes in person's condition. Provide stimulation without stress. Visits, outings, etc. are good only if the ill person is interested and can function acceptably.

Discovering this is a trial and error procedure. Families can help explore available community programs. Become a knowledgeable aggressive advocate and your relative will get better care and do better.

6. **Take care of yourself.** Families must take care of themselves. Share your frustrations with others. Join AMI/FAMI Support Groups. Enjoy outside interests, too. Increase your outside social contacts. Make sure all family members have their needs met, not just the sick person.

7. Remember: The future is unpredictable and **stay with the present.** Reduce expectations for a rapid recovery. Reduce pressure on the patient for performance. Modify overall expectations and strike a reasonable balance between realism and hope.

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### Communication Skills

Effective communication with schizophrenic patients is particularly important because they are so easily overwhelmed by the external environment. Skillful communication can make an enormous difference in the ability of patients and families to resolve the problems of daily living.

Good communication involves:

- 1. Knowing **when** to communicate
- 2. Knowing **what** to communicate
- 3. Knowing **how** to communicate.

### When to Communicate

Don't discuss something important when you are angry or upset. It's hard to think clearly, listen well, and focus on constructive solutions. Before talking to your relative, take as much time as you need to calm down.

### What to Communicate About

Since schizophrenia is a serious disorder that affects not only the patient but others around the patient, there are usually several problem areas that family members want to address. Bringing up several problems at once will overwhelm your relative, so it's best to select one problem at a time. Choose one problem area that is really important, then focus on a specific behavior you'd like your relative to change. For ex., say, "John, please stop playing your radio so loudly after 10 p.m." Don't say, "John, you're too noisy at night."

### How to communicate

Communication has two levels, verbal and nonverbal. Verbal communication is the what you actually say. Keep all your verbal communication simple, brief, and specific. Nonverbal communication refers to how you say it--your tone of voice, posture, eye contact, facial expression, and physical distance between speakers. The nonverbal "message" that comes across is often more important than the the verbal message.

#### **Guidelines for non-verbal communication:**

1. Stand close to your relative, but don't crowd his/her personal space.
2. Convey interest, concern and alertness through your body posture and facial expression.
3. Maintain eye contact with your relative.
4. Speak calmly and clearly.

#### **Expressing positive feelings.**

1. Look at the person.
2. Say exactly what the person did that pleased you.
3. Tell the person how their behavior made you feel. (Bad ex.: "You are nice to have around the house." Good ex.: "I like it when you do a nice job cleaning the kitchen").

#### **Making a positive request.**

1. Look at the person.
2. Say exactly what you would like the person to do.
3. Tell how it would make you feel.
4. Use phrases like "I would like you to...." or "I would really appreciate it if you would....."

#### **Expressing negative feelings.**

Look at the person. Say exactly what the person did that upset you. Tell the person how it made you feel. Suggest how the person might prevent this from happening in the future. (Bad ex. "You are a frightening person." Good ex. "I get very nervous when you pace around the room.")

#### **Active listening**

1. Look at the speaker.
2. Attend to what is said.
3. Nod head, say, "Uh-huh".
4. Ask clarifying questions.
5. Check out what you heard.

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Following are examples of positive language that you can use with someone with NBD

From Dick and Betsy Greer, these statements can aide in communicating w/someone w/NBD.

## STATEMENTS OF ENCOURAGEMENT

### Phrases that display confidence

- "I know you'll do fine."  
you can handle it."
- "I'll trust you will work it out "You'll make it!"

### Phrases that recognize effort and improvement:

- "Look at how much you accomplished so far."
- "Looks like you put a lot of work into that."
  - "Looks like you made a real effort."
- "You took a lot of time thinking things through."
  - "You have done more than you realize."
- "If you look at your progress, you'll see that..." (be specific).
- "It took a lot of courage for you to follow through."

"

### Phrases that display acceptance:

- "I like the way you approach that."
  - "I'm glad you enjoy learning."
- "I'm glad you feel good when you succeed."
  - "You look pleased. I am happy for you."
- "Since you are dissatisfied, what could you do to improve the situation"
  - so you are more content?"
  - "I know you're really pleased with it."

"

### Phrases that acknowledge appreciation, strengths, and contributions:

- "I really appreciated your help; it made my job a lot easier and I was"
  - able to get everything completed."
  - "Your idea really helped us think things through."
    - "Thanks, that helped a lot."
- "We really need some help, and you have the special skills we need."
  - Would you help?"
  - "I really enjoyed hearing what you had to say. It helped."
  - "I can use all the help you would be willing to offer."

"

-- From the Family Reference Book of AMI-Van Nuys.

## BOUNDARIES

or "Why doing less for your relative shouldn't make you feel bad."

As a caregiver for someone with a neurobiological disorder ("NBD" formerly known as 'mental' illness) you may think:

"Since the other person needs so much done, I'll do absolutely everything I can for as long as I can."

...or

"Because the other person is so needy, I will do whatever they want, whenever they want, for as long as they want."

However admirable these thoughts appear, they can create problems for your caregiving. Here are two reminders.

\* You need to establish boundaries for your own good.

Yes, it's true - the other needs you. Yes, you can help, and yes, you may find meaning in doing that. But, no, you don't have to do it all. And, no, you don't have to do it to your own detriment.

Being always with another and doing constantly for another allows you no time to meet your own needs. And you have very important needs to be met. If you're not careful, you'll soon be on your way to exhaustion and burnout.

Some boundaries for you to set are physical. Some things are simply too strenuous for you to do. Some hours are too long for you to keep. Some chores you cannot continue to perform with relief.

Other boundaries for you to set are emotional. If you identify too completely with the other's pain or fear or other strong emotions, you will be in danger of making them your own. Your responsibility is to handle only one person's feelings - yours.

Remember also that setting limits to your caregiving will make room for other caregivers. Family members and friends may wish to share in these duties. It's one way they can cope with what has happened, and one way they can show their love.

\* You need to establish boundaries for the other person's good.

One way you can respect the other is to give them their own space. They need their privacy just as before - perhaps to read or meditate or write. They may wish to look out the window and do nothing at all. If you do not provide for this solitary time, the one in your care may not have the strength or the heart to do so.

The other person needs the freedom to do things on their own as a matter

of self-esteem, and perhaps for continued recovery. If you insist on doing too much, the other has too little opportunity to flex their muscles. And there are several kinds of muscles they may need to flex.

Good boundaries give the other this added benefit: you can be a more objective presence in their life. Your insight can be more accurate and your feedback can be more useful.

All in all, establishing boundaries is one of the most thoughtful things you can do. It can even draw you closer together.

An excerpt from Chapter 8 of: *When You're the Caregiver: 12 Things To Do If Someone You Care For Is Ill Or Incapacitated*, by James. E. Miller. (Courtesy VVAAMI)

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World Schizophrenia Fellowship Pamphlet #17 -

### **SCHIZOPHRENIA: HOW SHOULD ONE BEHAVE?**

It may seem odd to ask "How should one behave towards a person with schizophrenia or allied disorder." However, most people do not understand what it is that makes it difficult for people with the disorder to communicate. The general public feels embarrassed and sometimes frightened to hold a conversation with a person who has mental illness. This pamphlet tries to give some pointers as to how to behave and is for families and for the general public.

We have learned that we need to speak slowly and clearly to persons with schizophrenia: to make the sentences short so that they are not too complicated; to wait to make sure that what we are saying is reaching the person.

#### **Why is this technique useful?**

A person with schizophrenia replies: "My concentration often floats in and out so that I only hear part of a sentence. Maybe I will miss two or three words. This will make it very difficult for me to understand. Recently I went on a family outing. There were other families there and I could hear everything that everyone was saying to everyone else. The sound and all the people moving about came in on me so much I began to get quite frightened. I was agitated and irritated at the same time. I felt I wanted to defend myself in some way. My dad took me to a quiet place where we sat and had a cup of tea. We didn't talk about it. We just sat and drank our tea and I began to feel less threatened."

#### **Structure and Instructions**

We have been advised that people with schizophrenia need structure in their lives; that routines are comforting and predictable and therefore useful to someone whose medical condition often makes life unpredictable. It is suggested that it is useful to help them set up a schedule and a few tasks to accomplish. at certain times of the day or week.

### **Is it possible to achieve this?**

Some people with schizophrenia are very disabled or become disabled from time to time. It is not always possible for them to follow a schedule, although it is beneficial to try to maintain a definite routine. However, when your relative/ your client/ friend attempts a task but isn't able to complete it or does it wrong it is not at all helpful to say things like: "Can't you get anything right?" or "Let me do it!" even when you are very frustrated. Break tasks into simple components to create the possibility of success, and to encourage the feeling of being useful. Give only one instruction at a time.

### **Maintaining Equilibrium**

Sometimes you may feel you are walking on broken glass when your relative or someone you know is having a particularly difficult time. At that time you have to summon up all your energy so that you can maintain their trust while at the same time maintaining equilibrium at home. Here are some ideas towards that goal. Many of these behaviours should also be adopted by the general public.

- Be Friendly
- Be Accepting
- Be Encouraging
- Make time to listen
- Include them
- Treat them with respect

### **Avoid the following:**

- Being **patronizing**
- Being **critical**
- **Pushing them** into situations they are not comfortable with
- Being **gloomy**
- **Arguing** with them, or with others while they are present
- Giving them a **lecture** or talking too much
- Getting yourself into difficult situations with them.

Sooner or later when a person has Sz a crisis will occur. When this happens there are some things you can do to reduce or avoid the potential for disaster. Here are a few pointers:

- Remember that you **cannot reason with acute psychosis**.
- Remember that the **person may be terrified by his/her own feelings** of loss of control.
- **Do not express irritation or anger**.
- **Don't shout**.
- **Don't use sarcasm** as a weapon.
- **Decrease distractions**: turn off TV, Radio, dishwasher, etc.
- **Ask any casual visitors to leave** - the fewer people the better.
- **Avoid direct continuous eye contact**.
- **Avoid touching** the person.
- **Sit down** and ask the person to sit down also.

### **When people move**

Often, a relative or friend will move or change his circumstances in some way without informing anyone. Social workers and other mental illness professionals are inclined to tell parents to "Let him take responsibility for doing this," or "It will be a learning experience for her." This type of advice indicates to us that many people in the helping professions do not understand the nature of schizophrenia. Our advice differs.

We know from experience that many persons with Sz are often unable to take responsibility for informing others about such matters. If we leave them to do so we are likely to end up dealing with the much more complicated mess that will have to be sorted out when the consequences of this lack of action come about. Examples are: pension/social assistance cheque fails to arrive and the person is cut off from benefits; bank communications, bills, etc are not received and not paid. Rent is neglected; possessions are left behind; premises are left uncleaned. Our advice is look after these matters if you suspect your friend/ relative won't.

People like to feel that they are in control of their lives. Sometimes it is difficult to persuade someone with schizophrenia to do what is best for them. Thus it is useful to offer a choice. "Will you take a walk now or after lunch", might be a way to suggest a walk, a shower, or any activity that you may feel useful or enjoyable. People with schizophrenia often have feelings that change very frequently, so that what someone may refuse at this moment he/she may agree to do later in the day/week.

### **Going to the Doctor**

A lot of people of my acquaintance complain that all psychiatrists are good for is prescribing pills or giving injections ? and perhaps that's true. Some people seem to want to go to the psychiatrist and get some real counselling. They'd like to talk about their housing and they'd like to talk about what the psychiatrist can do to help them get back to work or at least what would be their strengths if they tried. I don't know whether anyone has a psychiatrist who will help like this. Usually it's See the social worker?. But one of the men I see when I go for my appointment says the social worker is never in when he comes for his appointment. The trouble with me is that I have such high anxiety just walking in the out-patient door that by the time the doctor says Come in?, all I want to do is get out of

there! So it's a case of him saying How've you been?? and me saying Fine? and then responding that way to every question he asks me. He's trying to help but I'm about to explode. So I guess all my psychiatrist is good for is prescribing pills.?

### **Holiday time**

I dread holiday times when families are all supposed to get together, eat and drink and generally enjoy each others' company. For me, times like these bring back feelings of disappointment, resentment, sadness and a whole host of other emotions. Christmas, for example, has not been a good time for me or the family for many years. There were times my brother was in hospital, times he was home but barely stable, times he had to be taken to hospital during the holiday, times the police came. If I dread it, what does it mean to him? When he thinks a lot is expected of him, he usually handles it well for a few hours, but after that he crashes? - I mean he retreats to his inner self, or he gets extremely agitated. Last year each visiting family member took my brother aside for a mini-visit, a one on one chat and that seemed to work a little. At least he knew everyone cared. But when it came to the big dinner he disappeared to his room. He just cannot process a lot of noise, people, snatches of conversation - it's just too much for him.?

### **Do you help frail old ladies across the street?**

Use some of that attitude in rethinking your treatment and interaction with a person who suffers from schizophrenia who may live near you. This doesn't mean that you need to be overly friendly, but don't ignore them, engage them in conversation, but don't be intrusive. People with Sz, like a physically frail person, cannot defend themselves as well as a person in full possession of physical powers. They are also often on heavy doses of medication which may slur their speech or make them react slowly. Take into account that sometimes the person may be anxious and may withdraw. Let people withdraw, but leave the door open. Maybe ask them to visit you when they feel they are able. Offer a cake or a plant or some other friendly gesture. Send or drop off a postcard/ greeting card with a brief, friendly message every so often.