

A Publication of



Mental Health Emergency Roadmap:

A Guide to Emergency Mental Health
Services in Johnson County

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MANY THANKS ...

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This Roadmap is for all the people who use it. May their struggles be lessened by this effort.

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Introduction

Why This Roadmap?

Families and individuals often face sudden and highly stressful mental health emergencies. Typically they don't know what they should do, and they do not have time to look up and read lengthy books and articles—which usually don't tell you what to do anyway. They need to know right away what to do. Each scenario included herein describes a highly stressful situation caused by mental illness that requires the family of the ill person to take immediate action and requires navigating the complex, and often confusing, mental health system. In each unit, the scenario is first graphically described. Then specific and recommended actionable guidance for dealing with that situation is presented. The idea is that a family or person suddenly facing a stressful mental illness emergency can scan the scenarios, choose the one closest to their situation, and then use the immediate, suggested guidance on how to begin to deal with their situation. Without such a guide during this period of uncertainty and anxiety, decision making can be confused, suboptimal, and delayed. The consequences can be serious. This is a practical guide written in plain English. We have attempted to avoid medical, bureaucratic, or academic terms that would not be familiar to most people seeking help.

The information provided in this *Roadmap* is presented as a supplement to, and not a substitute for, the knowledge, skills, and expertise of qualified psychiatrists, psychologists, physicians, and other health care professionals. The information has been obtained from sources believed to be accurate and reliable and is as current as possible; however, some information presented here may become outdated over time. The resources identified here may not encompass all possibilities, but any omissions are unintentional. Should you have additional health, medical, or disability questions or concerns, please consult a physician or other health care professional. The reader may go to the national NAMI website, www.nami.org, where information is updated regularly and where links to other relevant sites are provided. Although the focus of this *Roadmap* is on Johnson County, Iowa, the website of the Iowa NAMI office (www.namiowa.org) can also be useful, as can our local Johnson County NAMI website (www.namijc.org).

According to the 2002 report of the President's New Freedom Commission on Mental Health, the mental health care system in the U.S. is—fragmented and in disarray. It is a complex, poorly functioning disaster in need of a total overhaul. In 2006 the National Alliance on Mental Illness gave the state of Iowa an F in mental health care in its *Report Card on the States*. This was updated in 2009 to a D. The situation locally here in Johnson County is not as bad as in most Iowa counties, but it is still seriously deficient. The National Alliance on Mental Illness is working every day to promote the needed reform of mental health care; however, when a mental health emergency strikes you or your family, you need to deal within this system now. You cannot wait for reform. This guide will help you do that.

Documenting Your Family Member's Problem

Once you have taken the initial action you need to take, you will probably find you are dealing with a whole series of physicians, psychiatrists, social workers, disability clerks, etc. Each of them will want a description of the problem and the individual involved, so you should write a description of your—case—the name, age, sex, etc., of the person in question and description of the symptoms or problem behaviors. If your family member has had previous psychotic or depressive episodes, you need to include the name and phone number of the family member's current psychiatrist and information on previous hospitalizations in the description. This includes the names and addresses of the hospitals, the phone numbers of the psychiatric wards there, the names of the attending psychiatrists and social workers, the diagnoses, and the

names of the medications your family member was using. If you have a family member with a history of mental illness, you should keep all this information available in written form. Also, you should ask your family member to sign a release allowing his/her psychiatrist to provide you with information on your family member. A family member in recovery is much more likely to sign such a release than one in the midst of a mental breakdown. In the case of a housing or disability problem, include a detailed description of the family member and the problem. Then as you meet with successive providers, you can give each a copy of this written description. This will save you and them a lot of time and effort and will help ensure that they have an accurate picture of the problems.

Commitment Information

In some mental health acute crisis situations, it may be necessary to have a legal commitment. In an emergency, the Iowa City police department (319.356.5275) or the Johnson County Sheriff's department (319.356.6030) can help with this. Otherwise, commitment forms and information are available in the office of the Clerk of Court, located in the Johnson County Courthouse on South Clinton Street in Iowa City. The telephone number is (319.356.6060, extension 7). Commitment requires that at least two people sign a document saying he/she is a danger to self or others. (For example, one way in which a person can be a danger to himself or herself is failure to eat, leading to weight loss and endangerment of health). Only one of these people can be a relative. Typically, one of the signers is a relative and the other is a doctor, psychiatrist, or other mental health provider.

Sometimes there is no doctor or mental health provider available to serve as the non-relative signer. In such cases, the unrelated person who signs must be someone with knowledge of your family member's symptoms and behavior. When you do a commitment without a doctor or mental health provider's signature, both you and the unrelated person must go to the courthouse and write a description of why the person is a danger to self or others. The Clerk then takes these documents to the Judge and he/she determines if the commitment will be granted. If the commitment is granted, then you have to take the paperwork to the Sheriff's Office at the County Jail. You may have to wait until a deputy sheriff is free. The deputy sheriff will then ask for your help in locating the person. When the deputy sheriff locates the person, he/she is required to handcuff the person and transport them to the hospital in a sheriff's car. Successful commitment is contingent on having a psychiatric hospital bed available.

Commitment requires court approval and the initial commitment lasts only 72 hours. After this, a hearing is held to determine whether an extended commitment is justified. This hearing is usually held at the hospital, and the patient is present. At this hearing, both you (as a family member) and the hospital personnel (doctors, nurses, and social workers) can offer information, as can your ill family member. The patient is represented by a Mental Health Advocate appointed by the court. At the hearing, the patient sometimes voluntarily agrees to remain in the hospital. If the information presented warrants it, the patient is committed to the hospital until a doctor authorizes release. According to NAMI statistics, 70 percent to 90 percent of people with a mental illness improve with the proper treatment and support.

Planning Ahead for the Post-Hospitalization Period

If your family member is hospitalized, it is important to begin planning during the hospitalization period for what will happen after your family member is released from the hospital. After release, your family member may need assistance with obtaining psychiatric care in the community, housing, employment, and perhaps help with daily activities, such as money management and paying bills. Discuss these needs with the hospital social worker assigned to your family member. Ask him or her to call the Johnson County Mental Health and Disability Services office (MH/DS) at (319.339.6169) and find out what programs are available that are

appropriate for your family member and whether MH/DS can provide funds to those programs to cover the costs for your family member. As you will see in this document, some services are free but others are not. MH/DS can often find funds to cover the costs of the programs that are not free if the patient meets income and asset guidelines. It is important to have a plan in place before your family member is discharged. Otherwise, the situation upon discharge can be very stressful for both you and your family member.

Taking Care of Yourself

All of the situations described here are very stressful for the family member, co-worker, or care giver. It is important for you to take care of yourself to protect your physical and emotional health. If you feel that you need personal emotional support in a crisis like those described herein, call the Crisis Center Crisis Line at (319.351.0140), or call one of the volunteer lines provided by the National Alliance on Mental Illness of Johnson County (NAMI-JC). Call the NAMI-JC office at (319.337.5400) to find a helping telephone volunteer. These sources can direct you to the support you will need.

Psychotic Episode or Other Mental Health Problem of Adult Family Member, Friend, or Co-Worker

Scenario 1. My 19 year old son lives at home and attends the local Community College. For some time now, I have noticed a change in him—he seems preoccupied and tense. He’s become hard to talk to—I can’t get him to open up. Then when I got home from work yesterday, he came into the room and started to say some really strange things. He thinks there are evil spirits tormenting him. His behavior got stranger and stranger from there. I am really anxious about this. He has always been so normal. What should I do?

Response:

- First, call the faculty or staff at the community college he attends to see if they have noticed the same changes you are seeing (keep in mind the school may not release information without an authorization from your son).
 - Has he accessed services at school for mental health counseling?
 - Has he been removed/left class for inappropriate behavior?
- Next, see if you can get your son to go with you to your family doctor. He/she will probably run a number of tests to rule out a physical problem: tests for drugs, high or low blood sugar, infections, hypothyroidism, etc.
- If these tests are negative, ask your family doctor for a referral to a local psychiatrist or clinical psychologist, so your son can be evaluated for possible mental health problems. The psychiatrist or psychologist can then recommend treatment based on your son’s needs.
- You may need to accompany your son to the appointment and ensure that he is offered a confidentially waiver to sign so that information can be shared with you.
- The psychiatrist or psychologist may recommend either outpatient treatment or hospitalization. Outpatient treatment may be obtained at University of Iowa Hospitals and Clinics Psychiatry Outpatient Clinic (319.353.6314) or at the Community Mental Health Center for Mid-Eastern Iowa (319.338.7884) or from a private practitioner.
- The psychiatrist or psychologist may recommend that your son be admitted to a hospital. Here, in Johnson County, your options are the UI Hospitals Psychiatric Unit (319-353-6952) or Mercy Hospital (319.339.0300). There are also hospitalization options in Cedar Rapids, Iowa.
- If your son is a veteran, you should call the Veterans Affairs Medical Center at (319.338.0581). The VA Medical Center provides both outpatient and inpatient psychiatric services for veterans.

Scenario 2. My daughter has been living and working in a large city halfway across the country. We talk at least once a week and, until recently, she has seemed fine. She has had some problems with mental illness but has been doing well for two years now. All of a sudden, she doesn’t want to talk much anymore. She won’t give a reason when I ask. Then I got a call from a social worker in a hospital asking if I was related to her! She was in a hospital there, and they found my phone number in her possessions. They said she was in the Adult Psychiatric Ward with a psychotic episode. I don’t know what to do. What can I do? What should I do?

Response:

- Call the social worker back and ask that he/she ask your daughter to sign a release allowing the hospital to give you information on your daughter’s treatment, condition, etc. Without this release, the law does not allow the hospital staff to give you this information.

- Remember that even if your daughter refuses to sign the release initially, she might after a few days in the hospital. Also, even if she does not sign the release, you can still talk to the health care providers, but they cannot divulge specifics about her situation to you.
- You can, however, provide the hospital doctors and the social worker with information on your daughter:
 - You can tell them about her health history, background, employment, education, etc.
 - You can also provide them with the name and phone number of her doctor. You can provide the hospital with the name and phone number of her psychiatrist and/or psychologist if she has seen one in the past.
 - You can also give them the dates of her previous breakdowns, the hospitals she was in, and (if you have it) the names and phone numbers of the psychiatrists who treated her and the social worker involved.
 - If you know, you can tell them what meds she is on and what the dosages are. This sort of information can greatly improve the treatment your daughter can be given.
- Also, ask the social worker to give you the phone number to call (usually the county social services agency) to find out what social services will be available to your daughter when she is discharged from the hospital and remains in that area.
 - This includes follow-up treatment and counseling, support groups, and housing aid (if needed).
 - If you think your daughter will come to live in your city after release from the hospital, call the Johnson County Mental Health and Disability Services office (MH/DS) (319.339.6169) to find out what will be available for her in Johnson County.
 - If she will not be coming back to Johnson County, ask the Johnson County Department of Human Services to provide you with the phone number of the Human Services department in your daughter's county in the other state. Then call them.
- Finally, you might consider traveling to the city where your daughter is hospitalized to visit her.
 - You should be aware, however, that if she is very ill, she may refuse your visit, and you will not be able to see her.
 - This is more likely to happen if she has refused to sign the release form. You may want to get some indication from the social worker that she is willing to see you before traveling there.

Scenario 3. My son has had several severe psychotic episodes. When he starts to get sick, he spends more time driving. He says it relaxes him. Lately he has begun to show some of his previous symptoms when I visit him in his condo. Two days ago, he seemed in pretty bad shape to me. Now he is just gone! His condo is locked, and his car is gone. I think he got worse and just took off driving across the country. I don't know where he is or how bad off he is! What can I do?

Response:

- This is a very difficult situation, and there may be no perfect answer; however, you can try the following things:
 - If he has a cell phone, try to reach him this way.
 - If he has friends, call them to see if they know where he is.
 - If he has been working with a psychiatrist, call the psychiatrist to see what he/she knows. (The psychiatrist may refuse to provide any information if your son has not previously signed a release allowing him to do this; but, he/she can and will accept information from you).

- Check to see if his car or cell phone (if he has one) contains a chip that allows his whereabouts to be traced via GPS technology. Many cell phones and cars today have this feature.
- You should report him to local police and sheriff departments as a missing person.
 - The Johnson County Sheriff can be reached at (319.356.6020).
 - The Iowa City police department can be reached at (319.356.5275).
 - The Coralville police department's phone number is (319.248.1800).
 - If you can provide them with the make, model, year, and license plate number of your son's car, they will put this information in a nationwide law enforcement data base. Then, if police anywhere stop your son for any reason, they will report to the Iowa City police that they have located him.
- At some point you may just have to wait for him or someone else (for example, hospital personnel or police) to call you; however, you can do things that will make things easier in the future if this happens again—as may well be the case given your son's history.
 - Make sure your son has a cell phone or car or both that can be traced.
 - Give your son a card to carry in his wallet saying he has a mental illness and instructing the police or doctor to call your phone number or that of his therapist.
 - Also, you can ask him to enter an ICE (In Case of Emergency) phone number into his cell phone. This will likely be noticed by emergency personnel. Either of these allows emergency personnel to provide you with information on your son.

Scenario 4. My husband is clearly slipping into a mental illness. He mumbles strange things, rarely eats, does not bathe, and believes he is—being watched. He says the neighbors have—bugged our bedroom. He is losing weight pretty fast. He says there is nothing wrong with him, that I am the one who is—sick. I am telling him he needs help, but he says—I know my rights and—You can't force me to do anything. I'm sure I will have to try a legal commitment. How do you do this? What do you do?

Response: These behaviors are serious.

- First, see if you can convince him to go with you to your family doctor. The doctor will run tests to check for physical problems (blood sugar test, hypothyroidism test, tests for infection, etc.).
- If these tests are negative, ask the doctor to refer your husband to a psychiatrist. The psychiatrist may recommend outpatient treatment or hospitalization.
- Your husband may refuse to go to the family doctor or, if he does go, he may refuse the doctor's recommendations.
- If his symptoms remain serious, you may have to do a legal commitment.
- In an emergency, you may call 911. The Iowa City police (319.356.5275), Coralville police (319.248.1800), or the Johnson County Sheriff's Department (319.356.6030) can help with legal commitment.
- If it is not an emergency, commitment forms and information can be obtained at the Office of the Johnson County Clerk of Court, located in the Johnson County Courthouse on South Clinton Street.
- The commitment hearing requires that at least two people sign a document saying he is a danger to himself or others, and it requires court approval.
- In your husband's case, his failure to eat may indicate he is a danger to himself.
- This hearing is usually held at the hospital (if an emergency) or courthouse, and the patient is present.
- At this hearing, both you and the hospital personnel (doctors, nurses, and social workers) can offer information (testify), as can your ill family member.

- If the information presented to the court warrants it, there is an order for immediate custody and to transport. The patient will be held until the commitment hearing.
- This hearing has to be held within 72 hours.
- Also, the patient often voluntarily agrees to remain in the hospital. See the additional information on commitment in the Introduction to this document.
- According to NAMI statistics, 70 percent to 90 percent of people with a mental illness improve with the proper treatment and support. See also the discussion in the Introduction to this document on the need to begin planning while your husband is in the hospital for what will happen when he is discharged.

Scenario 5. My 22 year old daughter is obviously sick—mentally ill. When I tried to talk to her about it at her apartment, she said,—OK, I'll go to a hospital. She has not been in her apartment for days now, so I assume she did check herself into a hospital. In our community we have five hospitals with psychiatric wards. I have called them all, and they all say that the privacy laws won't let them tell me whether my daughter is in their hospital! I can't find out whether she is in a hospital or not, or if so, which one! I don't know where she is! What can I do?

Response: In this sort of situation, you do not have any ideal options.

- It is true that the hospital personnel are constrained from providing information to you about your daughter by the Iowa Mental Health Confidentiality law and by federal law. The law requires that this refusal be automatic; it does not depend on a request by your daughter not to share information.
- Your best bet is to call and ask to speak to one of the social workers or the head nurse in the adult psychiatric ward.
- Remember that even though the law does not allow them to give you information, you can give them information.
- In talking to the social worker, you may say,—I know you can't tell me if she is there; however, if she is there, here is some information on her that you will need.
- Then, you can give them her psychiatrist's name and phone number, her employer's name and phone number, her health history (including dates of previous episodes, hospitals where she was a patient, doctors' and social workers' names, etc.).
- If she is there, the hospital social worker will appreciate getting this information. In fact, you can often tell whether your family member is there by the level of interest the social worker shows in taking down this information.
If she is there, they will be very interested in obtaining the information. Often, this is their way of letting you know whether she is there without violating the law. Using this approach, you may be able to find your daughter.
- Once you have determined that she is a patient, you may be able to obtain some specific information.
- A clause in the state law provides that if you are the caregiver, or are providing caregiver oversight for your daughter, you are entitled to know her diagnosis, prognosis, and prescribed medications (Iowa Code, Chapter 228.8). You are entitled to request this specific information from the hospital. You may, however, need to file a formal written request to receive this information. Ask your daughter's hospital social worker for the procedures to follow for this request for information.

See the discussion in the introduction to this document on the need to begin planning while your family member is in the hospital for what will happen when he or she is discharged.

Scenario 6. I am worried about my sister. She and I are very close and spend much of our time together. My sister has not been herself for the past month, and I worry about her. She has stopped going on our morning walks that we have been doing for the last year. I went to visit her at her apartment last week, and she looked as if she had not showered in a week. She stopped showing up at work, which is not like her at all. I keep asking her what is wrong, and she just says that she feels exhausted, but she is sleeping all the time. She doesn't have any food in the house and is not eating well at all. She looks as if she has lost ten pounds. The family doctor could not find anything medically wrong with her. I know something is wrong, but I don't know how to help her. What should I do?

Response:

- Since the doctor could not find anything medically wrong with your sister, you can ask that doctor for a referral to a mental health professional.
- The Community Mental Health Center of Mid-Eastern Iowa (CMHC) also provides psychiatric care and outpatient therapy on a sliding fee scale, but they usually have a waiting list to get an appointment. In Johnson County, the Community Mental Health Center of Mid-Eastern Iowa is located at 507 East College Street. The phone number is (319.338.7884). The University of Iowa Hospitals and Clinics Psychiatric Outpatient Clinic also provides outpatient psychiatric care (319.353.6314). Like the CMHC, it also usually has a waiting list.
- In the meanwhile, one idea is to have you or someone close to your sister go stay with her at her house. That person could help your sister with basic daily tasks such as grocery shopping, cooking, cleaning and support. It is also important to ask her if she has thought about suicide. The Crisis Center (319.351.0140) is a good place to call to obtain tips for asking loved ones about suicide and assessing the lethality of the situation.
- Since she is also missing work, it would be good to find out if she has notified her employer. If not, contact her place of employment (with her permission) to let them know about her situation to see if you can prevent her from getting fired.

Scenario 7. I have a co-worker who has changed quite a bit in the past six months. Her interaction with co-workers has decreased. Her hygiene has slipped (dirty hair, clothes with stains). She misses work at least one to two days per month. (She has plenty of paid sick time; prior to six months ago, she rarely missed work). Several times in the past two months, co-workers have helped her with assigned work projects to get them done on time so she won't get into trouble with the supervisor. I have expressed my concern to her and asked if she would like to talk sometime. Her response is vague: -I'll get back to you. Who should I talk to about these concerns?

Response:

- There are limits on what you might be able to do as a co-worker.
- You may continue to offer support and provide a non-judgmental listening ear.
- You might want to increase the frequency of your offers to talk.
- If your employer has an Employee Assistance Program (EAP), suggest to your co-worker that this could be a source of help for her.
- If you know any of her family members, you might discreetly approach them and discuss the situation with them.
- If none of these efforts result in improvement, at some point, you may need to go to her supervisor with these concerns. If so, if you think that your co-worker's supervisor may not be well informed about mental illness, and might react badly, consider having someone else

in the room (an upper level supervisor, a Human Resources person, or someone else you believe is educated about mental illness) when you discuss this situation.

- Backlash is a possibility, but doing nothing is also not acceptable. Protect yourself and your co-worker from the mental illness stigma as much as possible.

Scenario 8. My sister's husband committed suicide three years ago. She did well for the first year, but now she seems to be getting worse instead of better. She doesn't come to any family functions and when I call, she lets the answering machine pick up even when I know she's home. She doesn't talk to us anymore. What can we do?

Response:

- Sometimes there is a delayed reaction to a major loss of the kind your sister suffered. Grieving is a long process, especially when the grief is complicated by suicide.
- Encourage your sister to seek support. It is possible that the appropriate support would help your sister get through this difficult time.

Here are some sources of support:

- The Crisis Center has a Suicide Survivor Support Group that might be helpful. This group meets the first Thursday of each month from 7:00 p.m. to 8:30 p.m. The Crisis Center is located at 1121 Gilbert Court, Iowa City 52240. Their phone number is (319.351.0140), and their website is www.jccrisiscenter.org. This service is free.
- Along these same lines, Iowa City Hospice provides grief counseling and support groups. Iowa City Hospice is located at 1025 Wade Street, Iowa City 52240. Their phone number is (319.351.5665) or (800.897.3052). Their website is: www.iowacityhospice.org. The support services offered by Iowa City Hospice are free.
- The Community Mental Health Center can provide monitoring and some psychotherapy. The Community Mental Health Center of Mid-Eastern Iowa is at 507 East College Street in Iowa City. The phone number is (319.338.7884). This center serves Johnson, Cedar, Iowa, and Washington Counties.

The kind of support described here is often enough to turn things around for someone like your sister. If there is still no improvement after a month or so, see if you can convince her to see her family physician—for a checkup.

- Talk to her doctor ahead of the appointment. The doctor will run tests to check for physical problems (blood sugar test, hypothyroidism test, tests for infection, etc.).
- If these tests are negative, ask the doctor to refer your sister to a psychiatrist. The psychiatrist may prescribe medications that might help.

Scenario 9. My mother and father have been married for 40 years. Lately, my father is losing patience with Mom's need to check all the electrical devices in the house over and over before leaving the house or going to bed. He says they are late for everything because of this ritual. He has told her to stop but she continues. Mom says she is just being careful. Now Dad has asked me to talk to her. What can I tell my father?

Response: Compulsive behavior of this sort is well known to psychiatrists and psychologists.

- Tell your father that your mother may have a treatable mental illness.
- If your mother rejects such a suggestion, the following might work:
 - Have your father convince your mother to go to the family doctor for a checkup; she may resist this less than an immediate trip to a psychiatrist.

- Before the appointment day, your father should write a detailed description of your mother's behavior and send it to the doctor, or he could convey this to the doctor by telephone.
- Your father (or you) should ask the doctor to explain to your mother that she needs to see a psychiatrist and/or a psychotherapist, and he/she should recommend one or both.
- If your mother trusts the family doctor (which is usually the case), she will follow his/her advice.
- Today there are medications that help to reduce the sort of behavior your mother is displaying; however, it is usually more effective to include psychotherapy along with medications. The purpose of the psychotherapy is to train people to control the impulse to engage in compulsive behaviors. Ask the psychiatrist about the benefits of medication and psychotherapy.

Scenario 10. I just got married, and it is the first time my husband and I have lived in the same house. He takes a shower when he gets up and before he goes to bed. He showers after the slightest physical activity, and if I get home last from work, there are wet towels in the bathroom. Now I learned that he takes a shower at his place of work, both before and after his shift. I think something is wrong with him, but he denies it. I don't want to start off our marriage with this between us. How can I help?

Response:

Compulsive behavior of this sort is well known to psychiatrists and psychologists:

- Talk to your husband and see if you can get him to accept that he may have a treatable mental illness.
- If he rejects such a suggestion, the following might work:
 - Convince your husband to go to the family doctor for a checkup; he may resist this less than an immediate trip to a psychiatrist.
 - Before the appointment day, you should write a detailed description of your husband's behavior (in even more detail than you gave above) and send it to the doctor with an explanatory note.
- You should ask the doctor to explain to your husband that he needs to see a psychiatrist or a psychotherapist, and he/she should recommend one or both.
 - If your husband trusts the family doctor (which is usually the case), he will follow his or her advice.
 - Today there are medications that help to reduce the sort of behavior your husband is displaying; it is usually more effective to include psychotherapy along with medications.
 - The purpose of the psychotherapy is to train people to control the impulse to engage in compulsive behaviors.
 - There are techniques that people can learn that help them overcome these impulses.

Scenario 11. My wife was involved in a traumatic event last year involving a violent crime. She wasn't hurt, but now she's having nightmares. Last week, she came home terrified. She thought she saw the man again, but that's not possible. She's afraid to go anywhere where there are more than a few people. How can I help her?

Response:

- Explain to your wife that reactions of this sort to traumatic events are not uncommon and may last for years if untreated.

- Explain that these fears and anxieties can be reduced by medication and psychotherapy.
- See if you can convince her to go with you to a psychiatrist or clinical psychologist specializing in Post Traumatic Stress Disorder (PTSD).
- Call the Community Mental Health Center, 507 East College Street, in Iowa City (319.338.7884) and ask them to provide you with the names of clinical psychologists and psychiatrists who work with PTSD.
- Our observations are that the optimal treatment of PTSD usually requires both medications and psychotherapy. The National Center for PTSD has a website that provides useful information (www.ncptsd.va.gov).
- Another resource that could be helpful for your wife is the Victim Witness Coordinator for the Crime Victim Compensation Program. This service is located in the Johnson County Attorney's Office and can be reached at (319.339.6100).
 - Must report crime to local law enforcement within 72 hours.
 - Must file an application for the program within two years from the date of the crime.
 - It will take up to eight weeks to determine if you can be helped by the program.
 - Depending on timing, the program can pay bills related to the crime that are not covered by insurance or other sources, up to a designated amount.

Scenario 12. My son returned from a tour of duty in Iraq recently. He said he couldn't wait to sleep in his own bed. For a while, he seemed to pick up right where he left off. Now he tosses, talks in his sleep, and wakes up in a sweat. I often find him pacing the floor in the living room in the middle of the night. He jumps when I touch him or even when the phone rings. What can I do to help him?

Response: The symptoms your son is experiencing are very common among combat veterans. There are services available specifically for veterans. Here are a few of the resources available.

- Veteran's Administration (VA) Medical Center provides a full range of outpatient and inpatient services within the VA health care system. They also have a staff member assigned to suicide prevention. They are located at 601 HWY 6 West in Iowa City. Their phone number is (319.338.0581, Extension 5400).
- The National Suicide Prevention Lifeline has a hotline dedicated for veterans. Just dial (1.800.273.8255 and press 1).
- The Vet Center provides readjustment counseling for returning veterans at no cost. They are located at 1642 42nd St. NE in Cedar Rapids. Their phone number is (319.378.0016).
- The American Legion has a list of referrals that may help you. The local American Legion is located at 3016 Muscatine Avenue in Iowa City. There are also several other veterans' organizations that provide services; ask the VA Medical Center for a list.

Here are also some websites that you may find helpful:

- National Center for PTSD
www.ncptsd.va.gov.
- U.S. Department of Veterans Affairs
www.va.gov.
- U.S. Department of Veterans Affairs, Seamless Transition Home
www.oefoit.va.gov.

Operation Enduring Freedom (OEF) and Operation Iraqi Freedom (OIF).

It is sometimes the case that returning veterans will resist treatment because of the stigma attached to admitting needing help. This is especially likely to be the case for military personnel still in active service. If you encounter such resistance, it would be advisable to have a plan to deal with it. Consult with case workers at the VA Medical Center for ideas on how to deal with this.

Scenario 13. I don't know if this is an emergency or not. My 67 year old father lives in Iowa City and has a history of mental illness. I am the only family he has, and I live in Philadelphia. I can usually keep in touch with him by telephone and e-mail, but for the last week, he has not answered his phone and has not replied to any of my emails. He doesn't have friends I can call, and I don't know his neighbors or have their phone numbers. I am worried about him, but I don't want to fly all the way to Iowa City and perhaps then find he is fine. What should I do?

Response:

- If you call the Iowa City police department (319.356.5275), they will do a—wellness check on your father and report back to you.
 - They will send someone over to his house to see if he is at home and is OK.
 - If necessary, they will talk to his neighbors to get additional information.
 - When you call the Iowa City police, be prepared to give them your father's address and telephone number, and any other information you think might be relevant.
 - It is possible that you will learn that your father is experiencing mental health problems. If this is the case, find the scenarios in this Roadmap that most closely match your father's situation, and examine the advice given therein.
- You may also want to call Elder Services (319.338.0515). Elder Services provide a variety of services for senior citizens. These services can be useful whether or not your father is experiencing mental health symptoms. These services include family care giving, counseling, mowing lawns, light house cleaning/chores and home delivered meals.

Mental and Behavior Problems with Your Minor Child

Scenario 14. We have a problem with our daughter which has gotten worse—to the point that we are desperate. She was an exemplary child up to age 9, when she began having—temper fits, becoming suddenly consumed with anger and defiance for no apparent reason. She is 12 now and these episodes have become much more frequent and last much longer. She now has trouble sleeping and often seems to be in a hyper-energized state, talking very fast and jumping around from subject to subject. At other times she seems very—down, just about the opposite extreme. In fact, she rarely behaves normally. Her anger and abusive behavior towards us and others has become intolerable, and she is a serious problem for her teachers in school. We are at a loss. The school principal said she can be referred to the services offered by the Grant Wood Area Education Agency, but we don't know what that would involve or whether it would help. What should we do?

Response:

- It would be highly beneficial if you would accept the offer to have your daughter referred to the Grant Wood Area Agency for an assessment/evaluation/behavior treatment program and possible referrals to other sources of help, such as psychologists and/or psychiatrists. Their professionals can provide her with help in improving her behavior and performance in school.
- Also, teachers are becoming better informed about mental illness in children. The National Alliance on Mental Illness of Johnson County has for some time been providing informational booklets about mental illness in children to school principals and teachers in the Iowa City Community School District.
- Your daughter may also need to be seen by a child psychiatrist. This can be done through the University of Iowa Hospitals or by a private psychiatrist. The phone number for Child

Psychiatry at UI Hospitals is (319.356.1188). The UI Child Psychiatry unit can provide evaluation, consultation, and treatment in cases of this sort.

- The kinds of behaviors your child is displaying often signal the development of a mental illness at a later age, so it is very important to get a diagnosis and begin treatment as soon as possible.

Scenario 15. My daughter was a straight A student, very popular, and a joy to have around. Around puberty, everything changed, and drug use started. Then, when she was 19, she had several psychotic breaks while doing drugs. The psychosis did not subside after the illicit drugs left her system, and she was put on medication for her psychosis. She has been diagnosed with schizophrenia, but still, on occasion, uses drugs and alcohol. Because she still uses drugs, she believes her mental illness is not real, that it is a drug-induced state that will go away. She wants to go off her medicines. What should I do?

Response:

- The use of drugs and alcohol by persons with severe and persistent mental illness is extremely common. It is called a dual diagnosis: mental illness and substance abuse.
- Drug use does not cause a mental illness, but it can trigger the onset of the illness.
- It is very important that your daughter receive treatment for both her mental illness and her substance abuse.
- There is a dual diagnosis treatment outpatient program at University of Iowa Hospitals and Clinics, called the Partial Program. It combines mental health and substance abuse therapy. Call (319.356.7934).
- Students may visit Student Health Psychiatry, but typically this service does not offer dual diagnosis treatment.
- There are other dual diagnosis programs in Iowa, but you should be very cautious about inpatient substance abuse programs. They do not always understand mental illness and can make matters worse.

Here is more information about the dual diagnosis program at the UI Hospitals and Clinics:

- Dual Diagnosis or Partial Hospitalization Substance Abuse service is available to help patients who need intensive treatment but do not require the security or intensity of inpatient care. The program focuses on moving patients into less structured outpatient programs. Patients participate in structured therapy programs during the day and evening and spend nights at home. This cost-effective strategy helps transition individuals back into community life. Call (319.384.8765) or (319.384.8999).
- Dual Diagnosis Clinic. Special services have been developed to care for individuals who have either a medical or mental illness in combination with a substance abuse disorder. UI Behavioral Health offers a dual diagnosis clinic to address these complex needs in one setting. Patients undergo an evaluation to help them and their health care professionals better understand the nature of substance abuse problems in conjunction with other psychiatric or other symptoms. An individualized treatment program is then developed that may include individual and group counseling, and medication. Addressing all the patient's medical and behavioral health needs at once provides greater success for addiction recovery. Referrals: Call (319.384.8765) or (319.384.8999).
- Intensive Outpatient Program. The Intensive Outpatient Program (IOP) provides primary treatment intervention for people who are experiencing substance abuse problems. The program is tailored to meet each individual client's needs. Clients receive from nine to twenty hours of treatment per week. The program includes education, group therapy, and family therapy as needed. Call (319.384.8765) or (319.384.8999).

Scenario 16. Our nine year old daughter Anna is just starting fourth grade, and we cannot get her to go to school. She insists that the school has a rotten smell and that kids tell lies about her. When we ask what kids or what lies, she gets more and more upset, cries and carries on until she curls up with her arms around her knees and moans about her stomach hurting. Sometimes she even throws up. We've talked to her teachers and principal, and they can't figure out what smells bad to her or who's upsetting her. She's never had problems with either kids or teachers—she's a quiet little girl who's too shy to make trouble. Our family doctor told us that what we had to do was check her temperature, and if she didn't have a fever, we should physically carry her into the car, if necessary, then into the school and stay there with her only until she's calm. We've tried that, but she just keeps wailing and saying the school's making her sick. Once when we did leave her, she even ran from the building. The principal says this is all too disruptive, that we need to take Anna to see a child psychiatrist or psychologist for treatment, or they might have to put her on homebound instruction. We see the problem, but we're sure that there must be some physical reason for her problems, or that she's got a super-sensitive sense of smell, or that some kids have terrorized her in ways the school hasn't found out. We certainly don't want her viewed as being—mentally ill and needing a psychiatrist when she's only nine. What should we do?

Response:

- The principal most likely has experience in the education of all types of children and therefore is a good source of advice. We recommend you follow the principal's advice.
- Recent research has shown how early in life the brain disorders that are serious adult mental illnesses begin to show their first symptoms.
- According to a report of the largest survey ever of the nation's mental health: **“One-half of all lifetime cases of mental illness begin by age 14, and despite effective treatments for the disorders, there are long delays between the onset of symptoms and seeking treatment”**. The report goes on to note that **the longer the delay, the greater the chance that a second or third disorder will be added to the original problem. Disorders that go untreated through adolescence are associated with such poor outcomes as school failure, teenage childbearing, unstable employment, early or unstable marriage, and violence.** *
- Anna's problem seriously interferes with her ability to function normally in everyday life, and the family doctor's advice, which would help most children get over a transitory problem, has not helped. She should have a full evaluation and ongoing services from a specialist in children's mental health.

*National Co-morbidity Survey Replication, report published in the June 6, 2005 issue of *the Archives of General Psychiatry*.

Worry about Possible Suicide

Scenario 17. My 17 year old daughter's friend contacted me today and told me that she was worried that my daughter was going to hurt herself. I had wondered if something was wrong because she had been acting strangely. She used to be a straight—All student, and now she is skipping school and has stopped doing her homework. She dropped out of ballet classes which she had been very passionate about up until now. She has stopped going out with her friends and keeps to herself most of the time. She told her friend that she would be better off without her and that she didn't want us to cry at her funeral. I am so worried that I can't think clearly. What can I do to help her?

Response: You are right to think this is a frightening situation. Based on what your daughter's friend has told you, it sounds as if your daughter needs to get help right now.

- Talk to your daughter openly about her thoughts of suicide.
- Find out if she has a plan to kill herself and when she plans to do it. As difficult as this may be, it is very important that you remain calm and talk to your daughter about the reasons she is feeling this way without judging her answers.
- The more you can get her to talk openly about what she is going through, the more she will feel supported and hopeful that things can get better.
- The Crisis Center has a 24 hour crisis line (319.351.0140) that can help you assess the lethality of your daughter's situation and help you figure out what to do next. Until you have a better idea of what your daughter is going through, it is a good idea to make sure that she is not left alone. Call her school counselor to inform him/her of the situation so that they can monitor her at school.
- If your daughter shows a sudden improvement in mood or a new calmness, this does not mean her problems are over. Sometimes people show this change after they have finally decided to kill themselves, and their mood—improves because they feel they will soon escape their pain and torment. You must continue to be alert and watchful.
- If after talking with your daughter, you feel that your daughter is at immediate risk of killing herself, you can take her to the UIHC emergency room. Your daughter will be seen by an on-call psychiatrist who will evaluate the situation and determine the best course of action. When dealing with suicide risk, it is better to err on the side of caution.

Scenario 18. Our twenty-five year old son has not been himself in recent months after a series of setbacks in his life. He is in school but not able to stay focused on his studies. His fun-loving spirit seems subdued. He has withdrawn from his friends and doesn't want to see anyone who has known him in the past. He is having trouble getting out of bed in the morning or following any of his usual routines. Even playing the piano, which was a passion for this accomplished musician, seems to have little appeal. We believe he not only has contemplated suicide but actually tried to take his life unsuccessfully on more than one occasion. We have discovered that he has been looking on the internet for ways to end his life. He won't tell us what he's thinking. We are frightened.

Although he has been seen by psychiatrists and social workers, they seem not to be picking up on the things we're seeing day to day, but because of the privacy laws, they won't speak to us directly because he is an adult. Admittedly, we don't really understand what he's going through. We've never experienced this kind of depression. We're worried sick and are not sure where to turn for guidance.

Response: Someone who you believe is seriously suicidal needs immediate attention. This may require immediate hospitalization, if only to protect him from himself. This could require involuntary hospital commitment. For information on this, see the section on Commitment Information in the introduction to the Roadmap. If necessary, consult an attorney.

In the view of many health professionals and lay persons, psychiatry, as practiced by many today has come to rely on medication to the exclusion of serious use of psychotherapy. In many practices, there is minimal or intermittent follow-up. Because of the danger your son faces, you must be his advocate.

- Advocate for regular psychotherapy as part of his treatment regimen. If it is inadequate in your judgment, look to others for help. If the psychiatrist does not follow-up with weekly contact, demand that he or she do so.
- In a teaching hospital setting, make sure that he has regular appointments and follow-up with a staff psychiatrist who will follow his case from week to week. Don't be satisfied

with having the primary care delivered by residents who are psychiatrists-in-training and may have limited experience with such cases as your son's.

- If you believe hospitalization is required, and if you are not offered placement for your son in a facility appropriate to his condition, be persistent in your request that they find a bed for him in an appropriate facility, even if it is unconnected to their practice.

The bottom line is that a life is at risk. An unresponsive system must be made responsive. Seek the help of a family physician, an attorney, a friend knowledgeable about the health care system, or NAMI. In the case of NAMI-JC, we may be able to put you in contact with others who have faced such circumstances, or who would be prepared to join you in advocating on behalf of your son.

Violent Family Member

Scenario 19. My 27 year old severely mentally ill son has lived with us for the last ten years. His diagnosis is schizo-affective disorder. My husband is the payee for him in connection with his Social Security Disability payments. He gets very angry with us when my husband does not give him money every time he asks us for it. He has assaulted my husband on more than one occasion and threatens to kill us in our sleep. We feel like prisoners in our own home and sleep with our door locked at night. We have had him committed in the past, but they only keep him for a few days because he takes his medicine and does fine. When he gets home, he refuses to take his medicine, and he goes right back to the same violent behaviors as before. My husband and I are exhausted and don't know where to turn. What can we do?

Response: This sounds like a very scary situation. You have tried a lot of options, and nothing has worked which leaves you feeling hopeless.

- It is important to have frequent communication with your son's psychiatrist to keep him/her updated on your son's behaviors. Even if your son has not signed a release allowing his psychiatrist to give you information, you can give the psychiatrist information.
- If he already has a case manager, you should contact him or her to express your concerns. If he does not have one, call the Mental Health and Disability Services (MH/DS) program of Johnson County to see if they can apply for case management and services.
- Many programs require a source of funding to pay for the program costs, and MH/DS has access to sources of funds for this purpose. They may be able to place your son in a home that cares for people with mental illness that can no longer live safely on their own, such as Birch House or Chatham Oaks.
- You may have to state to them that living with your son has not worked out and request that they find him an alternative living situation where he can receive the needed support services. MH/DS is located at 855 S. Dubuque St, Ste. 202B, Iowa City, IA 52240. The phone number is (319.339.6169). When you call, ask for an intake worker. Also, contact the Johnson County Mental Health Advocate (319.430.7278) and see if this office can provide services for your son. The advocate is currently Veda Higgins.
- It also sounds as if a large part of the conflict stems from your husband being the payee. It is possible to have an agency act as the payee which may eliminate a lot of the conflicts you are currently having. When you call MH/DS, ask them about this possibility.
- You can also see if your son qualifies for the IMPACT Program (Integrated Multidisciplinary Program in Assertive Community Treatment). This excellent program assists people with severe mental illness that have had multiple hospitalizations due to their mental illness.

IMPACT provides intensive treatment, support, and rehabilitative services at home and in the community. These include medication management, counseling, day-to-day problem solving, vocational services, and treatment of substance abuse. Staff are available 24 hours a day, seven days a week and include a psychiatrist, psychiatric nurses, and rehabilitation counselors from various disciplines. Call (319.356.1754) or (877.384.8999).

Mentally Ill Family Member Arrested and Jailed

Scenario 20. My 22 year old son was arrested last night. He had gone to the local grocery store and begun spraying the food and customers with Raid bug spray. The police arrested him and thought he was on drugs, but his blood work showed no trace of drugs. He kept talking about bugs everywhere while he was in his jail cell. He has had spells of mental illness off and on over the last four years, but he has never been arrested and put in jail. We are told he could receive a jail or prison sentence for assault. What should I do?

Response: Johnson County has a Jail Alternatives Program that is specifically designed to help people with mental illnesses who become incarcerated.

- It is important that you contact this program to let them know that your son has a diagnosed mental illness and is currently in jail.
- You can reach the Jail Alternatives Coordinator by calling (319.339.6169).
- Your son will be assigned a worker who will help him navigate the legal system and hook him up with treatment programs in the community that work with people in his situation. The Jail Alternatives Program deems some mentally ill people who have been jailed to be too dangerous for community programs outside of jail; however, based on the information you provide, this will likely not be the case for your son.
- It helps if the victim of the crime requests that the perpetrator be sent for mental health treatment rather than be incarcerated. If you could get the local grocery store owner or manager to request that your son be sent for treatment rather than jailed, he may be more likely to get into the Jail Alternatives Program.
- It is also important that he have a lawyer present. The Iowa Bar Association maintains a list of lawyers (with their specialties) who will offer a 30 minute consultation for \$25. If further legal assistance is needed, you will need to negotiate fees. The website is www.iowafindalawyer.com. Their phone number is (515.243.3179). Their office is located at 625 E. Courts St., Des Moines IA, 50309.
- If you cannot afford a lawyer, your son will be assigned a lawyer to defend him. Make sure to tell his lawyer about his mental illness history and the name of his psychiatrist.
- Also, check with his lawyer to see if your son's case can be heard by a judge who is known to be educated about mental illness. Judges are not all equal in this respect.
- It is important that you make the effort to keep your son out of the jail and prison systems and get him into a mental health treatment facility where he can obtain proper treatment for his mental illness—treatment that is not provided in jails or prisons. Changes in the mental health system in the 1970s and 1980s in Iowa and nationwide led to the dumping of mentally ill people out of hospitals and onto the streets where many became homeless, many became victims of crime, and many wound up in jails and prisons. In fact, today large percentages (from 20 percent to 60 percent) of incarcerated people have a mental illness. The percentage in the Iowa state prison system is 40%.

Medication Problems

Scenario 21. My mother has done well on her meds for about four years now. Most people would never know she has a mental illness. (Her diagnosis has never been clear). But now she has quit taking her meds! She says she has not had a problem for four years, so she must be over her mental illness problem—cured. Yesterday while talking to her, I found out she has not been taking them for over a month. She denies it, but she is already showing the effects of this, she is already somewhat paranoid and suspicious of me and everyone else. I know it will get a lot worse if she does not go back on her meds, but she refuses to do so. What options do I have? What help can I get with this problem?

Response:

- It is very common for people with mental illnesses that have been under control for long periods of time through medication to begin to wonder if they still need the medications. They often come to believe that since they have had no problems for a long time (four years in your mother's case) that perhaps their mental illness has just gone away. They think that maybe they—got well and no longer need medications.
- One of the most difficult concepts to get across to people with a mental illness is that such brain disorders produce symptoms that can usually be controlled with medications and psychotherapy, but there is no—cure as yet.
- A person with a mental illness can go into recovery and remain in recovery for a long time, leading a fairly normal life. But the mental illness, a biochemical brain condition, is still there and can return. In this sense, mental illness is like many physical illnesses, such as diabetes.
- Explain to your mother that she has not had problems because of the medications and that if she stops taking the prescriptions, the problems will reappear. She might then start taking her prescriptions again.
- You should be aware that there are two reasons why it is hard for the mentally ill to accept this permanence:
 - First, some physical illnesses do go away with time, and everyone would like to think that is the case for themselves.
 - Second, and this is very important, when people with a mental illness stop taking their medications, *there is no immediate negative consequence*. Instead, it sometimes takes weeks for the symptoms to begin to reappear. In the meantime, the person feels he or she was right in thinking they did not need the medications, because they have been feeling great for weeks (and they have also escaped the unpleasant side effects, if any, of the medications). This same problem sometimes occurs with other illnesses such as hypertension (high blood pressure) or diabetes. Explain to your mother that if she stops taking her medications, she might feel good at first, but the symptoms will reappear as the medicine wears off.
- In the case of mental illness, however, by the time the symptoms re-appear, the person is often no longer rational enough to realize it was a mistake to stop the medications. It can be hard to convince them to restart them.
- Mentally ill people often have a condition called anosognosia in which they cannot recognize that they are ill. Because mental illness affects the brain, mentally ill people often cannot realize that they actually have an illness. This condition is a symptom of the illness itself.
 - This type of inability to realize there is something wrong also occurs in people after a stroke, which also causes an abnormality in the brain.
 - When anosognosia is an issue, convincing someone to take their meds is even more complicated. The most effective approach is to point out how good things go when they take their meds and how badly things go when they don't.

- Do not argue with the person about whether they have an illness or not because it is not constructive.
- Encourage the person with mental illness to recall the positives when on their meds and negatives when they are without the meds. This gives them the—power to make the right decision.
- A good book to read to help in this situation is *I Am Not Sick, I Don't Need Help*, by Xavier Amador.
- What else can you do? You can call your mother's psychiatrist about this.
 - If your mother has earlier signed a release, her psychiatrist can discuss this situation with you in detail.
 - If she has not, you can still give the psychiatrist the information you describe in your statement and you can suggest that the psychiatrist call your mother and arrange an appointment as soon as possible.
 - Try to impress on the psychiatrist that you know your mother has stopped taking her medications, you are very worried about your mother's changed behavior, and you would like to turn the situation around before she has a breakdown and has to be hospitalized. Most psychiatrists take information of this sort very seriously.

Scenario 22. My wife has all along been very good about taking her meds. I see her take them every day, so I know she takes them, but lately they don't seem to be working. Her symptoms have started to creep back and are now getting worse. I need to do something before she has a full blown breakdown. What should I do?

Response: Your statement says nothing about any unusual recent stresses in your wife's life, so we assume nothing in her environment has been the trigger for this change.

- If this is so, and if she has in fact been taking her prescriptions properly and regularly, then the first thing to check out is the possibility that the medications have stopped working, especially if she has been taking these medications for six months or longer.
- The human body adapts too many medications and this adaptation may cause their therapeutic effect to disappear over time.
- The usual solution is to switch to another medication that serves the same purpose.
- If your wife is able and willing, encourage her to call her psychiatrist, explain the problem, and ask for a medication review. The psychiatrist may agree over the phone to prescribe new medications, and then may call your local pharmacy and authorize filling of the new prescriptions.
- On the other hand, if your wife's symptoms are already so severe that she cannot handle the problem, you may need to step in.
- If your wife has signed a release allowing her psychiatrist to discuss her case with you, then call him or her and report this situation and discuss it with him or her.
- Even if she has not signed a release, you can still call the psychiatrist and report this change in your wife's condition and behavior.
- You can suggest that perhaps the meds have ceased working. The psychiatrist may agree to change the medications over the phone and may call in the new prescriptions to your pharmacy. Find out from your wife (or from her psychiatrist) when her next appointment is.
- If it is more than a few days off, see if you can get the psychiatrist to call and reset the appointment for an earlier date.
- If she can be started on the new medications soon enough, it may be possible to turn her around without a breakdown and hospitalization.

Scenario 23. My husband has been on psychotropic meds for several years and has done pretty well, considering. Lately I have begun to suspect he is no longer taking his meds—or not

all of them. He says he is taking them and that I should mind my own business. It is hard to be sure, but, by my crude count, his pills are not going down over time as they would be if he took them on schedule. I think (but can't prove) he is lying about taking his meds, and he seems to be much more touchy and distant than before. What should I do?

Response: You are right in your attempt to be observant of your husband's compliance with his medications.

- It is very common for people with mental illnesses that have been under control for long periods of time through medication to begin to wonder if they still need the medications.
- They often believe that since they have had no problems for a long time (several years in your husband's case) that perhaps their mental illness has just gone away. They think that maybe they just—got well and no longer need medications.
- One of the most difficult concepts to get across to people with mental illness is that mental illnesses are permanent—they never—go away.
- A person with a mental illness can go into recovery and remain in recovery for a long time, leading a normal life. But the mental illness—a biochemical brain condition—is still there and the mental illness symptoms can return.
- In this sense, mental illness is like many physical illnesses, such as diabetes.
- Perhaps your husband does not believe this. If so, perhaps you can talk to him and convince him of this. Then he might start taking his prescriptions as he should.
- We assume from your description that you have not noticed anything happening in your husband's life that might be making him—more touchy and distant, since you do not mention any recent stressful events.
- What else can you do?
- You can call your husband's psychiatrist about this.
- If your husband has earlier signed a release, his psychiatrist can discuss this situation with you in detail.
- If he has not, you can still give the psychiatrist the information you describe in your statement and you can request that the psychiatrist call your husband and arrange an appointment as soon as possible.
- Try to impress on the psychiatrist that you are very worried about your husband's changed behavior and you would like to turn the situation around before he has a breakdown and has to be hospitalized.
- Most psychiatrists take information of this sort very seriously.

Scenario 24. When my son was discharged from the psychiatric unit at our local hospital, he was given 3 weeks of medications. But the earliest we could get an appointment for him with a psychiatrist was for 5 weeks later! We could not get an earlier appointment! He can't go without his meds for two weeks! What should I do?

Response:

- The first resort is your family doctor. Your family physician may be willing to write a prescription for your son's medications.
- There is a Free Mental Health Clinic in Iowa City at the Community Mental Health Center two Saturdays a month that is designed to help people with psychiatric needs until they can get in to see a psychiatrist. At this clinic, advanced psychiatry students work under the supervision of a psychiatrist, and they can renew your son's prescription. To set up an appointment email freementalhealthclinic@gmail.com.
- Or you can have the hospital call the Mental Health Center intake worker at (319.337.7844) with a referral, if the hospital is not willing to extend his prescription.

Scenario 25. My mentally ill daughter is on Medicaid and needs to find a psychiatrist or at least a medical doctor. The rock bottom minimum is having a doctor prescribe her meds for her. All the doctors she has called say they do not take Medicaid patients. What is she going to do? Is there anything she can do?

Response:

- The Iowa Department of Human Services website presents information on health care providers who accept Medicaid (Title XIX) patients. Their website is www.dhs.state.ia.us. Click on—Partners and Providers, then click on—Find a Provider, then—Health Care, and then select —Medicaid Providers.
- Also, there is a Free Mental Health Clinic in Iowa City two Saturdays a month that is designed to help people with psychiatric needs until they can get in to see a psychiatrist. To set up an appointment email freementalhealthclinic@gmail.com.
- You should be aware that some psychiatrists who do accept Medicaid patients may have reached their self-imposed—quota of such patients, and so they may not currently be accepting additional Medicaid patients.
- This will at least get her the prescriptions she needs immediately.
- Although many psychiatrists in private practice do not accept Medicaid patients, the psychiatrists at the Community Mental Health Center (507 East College Street, Iowa City 52240; call 319.338.7884) do accept Medicaid patients. If you contact them, they should be able to help you find a psychiatrist for your son or place him on their own waiting list.
- The University of Iowa Hospitals and Clinics Psychiatric Outpatient Clinic (319.353.6314) also accepts Medicaid patients; however, it also has a waiting list.

Scenario 26. My friend is on medication for mental health issues and seems to comply. She is not supposed to drink while on medication. Yet I hear from other friends that they have seen her drinking at several bars. I haven't seen her drink, and I try to offer activities (e.g., going to a movie or downtown Friday night music) where drinking is not involved. Should I talk with her and express my concern?

Response:

- Express your concerns to your friend in a kind way in a private setting.
- Ask her if her psychiatrist is aware that she is drinking and if she knows the dangers involved.
- Offer her support and your willingness to participate with her in activities that do not involve drinking.
- Suggest going to a bar with her, but drink non-alcoholic beverages.

Housing Problems

Scenario 27. My mentally ill son is now doing pretty well on his meds, but he needs a place to live. He is 35 years old and does not want to live with my husband and me anymore, and for that matter we really don't have room for him here either. He does not know how to find housing. Is there any help out there for people like him in the housing area?

Response:

- If he already has a case manager, call that person first.

- If he does not have a case manager, call the Johnson County Mental Health/Disability Services (MH/DS) at (319.339.6169) to apply for services and funding. Ask them about specific housing options. You may need to state that neither you nor he believes he should continue to live with you.
- Depending on his needs, the possibilities range from Chatham Oaks (a residential care facility) to his own subsidized apartment obtained through the City of Iowa City's Housing Authority. Also ask MH/DS about the Community Supported Living (CSL) services program, which provides help with activities of daily living, such as money management, paying bills, grocery shopping, cooking, housekeeping, etc. Any or all of these possibilities may have waiting lists.
- PATH is another possibility. PATH (Project for Assistance in Transition from Homelessness) is a program designed to aid those who need mental health services and are in need of housing.
- PATH would become relevant if your son were to become homeless.
- PATH services are free and can help with housing search assistance. Dori Dewey, the PATH worker can be reached at (319.430.7234). One possibility is Birch House in Iowa City. Birch House is run by Hillcrest Family Services and is located at 745 Pepper Drive, Iowa City 52240. Their phone number is (319.341.9849), (website: www.hillcrest-fs.org).

Scenario 28. My son lost his apartment when he went into the hospital. Now the hospital has caused a big problem for him. We thought Hillcrest or Chatham Oaks or some other agency could provide him with housing when he got out of the hospital. The hospital, however, did not provide adequate notification to these agencies in advance to save a space, so now he is discharged, and they don't have a place for him! Now he is basically out on the street (living in his car). What can he do? What can I do to help him?

Response:

Your son is in need of a residential care facility.

- Call the Johnson County Mental Health/Disability Services (MH/DS) at (319.339.6169) to apply for services and funding. MH/DS can often find the funds to cover the cost of housing for someone like your son.
- Ask them about specific service options for housing.
- Also, ask MH/DS about the Community Supported Living (CSL) services program, which provides help with activities of daily living, such as money management and paying bills.
- PATH is another possibility. PATH (Project for Assistance in Transition from Homelessness) is a program designed to aid those who need mental health services and are in need of Housing. Dori Dewey, the PATH worker, may be able to help with housing search assistance and can be reached at (319.430.7234).
- One possibility that he may mention is Birch House in Iowa City. Birch House is run by Hillcrest Family Services and is located at 745 Pepper Drive, Iowa City 52240. Their phone number is (319.341.9849), (website: www.hillcrest-fs.org). If you cannot pay for it personally, the PATH program may make a referral to MH/DS to help find a source of funding to pay the cost of the PATH program.

Scenario 29. My adopted daughter has a mental illness, but it is now—in remission. She is doing pretty well. Then she was fortunate to have a chance to move into subsidized housing in the city where she lives—a real godsend for her. At the last minute, they found out she had been arrested (during an incident related to an earlier breakdown), and they declared her ineligible for the housing. She was never convicted, only arrested, and was quickly released. This is very unfair. What can she do?

Response:

Because they are federally funded by money from HUD (Department of Housing and Urban Development), local Public Housing Authorities have to follow federal guidelines regarding criminal activity for anyone who applies for public housing or rental assistance.

- You can call the local public authority at (319.356.5400), and they can give you contact information for the city where your daughter lives.
- The mere fact of an arrest, with no conviction, should ordinarily not be grounds for refusal of eligibility for public housing, especially if the person's record is otherwise good.
- You should ask for an appeal.
- Submit documentation (from law enforcement or a legal notice) that she was arrested but not convicted.
- Indicate, if appropriate, that the incident was isolated and that she has had no legal problems since that incident.
- Also, there is a legal aid program that provides legal assistance to people like your daughter if they meet income guidelines and cannot afford to hire a lawyer. In Johnson County, this is Iowa Legal Aid, 1700 1st St. South, Suite 10, Iowa City 52240. The telephone number is (319.351.6570), website: www.iowalegalaid.org.
- You do not say whether the city your daughter lives in is in Johnson County, but if it is not, this Legal Aid office can refer you to the appropriate office in your daughter's city.

Disability and Financial Support Problems

Scenario 30. My son has a disabling mental illness. He has tried to work, but has not been able to hold a job. Last year he finally agreed to apply for Social Security Disability. I went to the local Social Security office with him and helped him compile the needed documents and statements from psychiatrists. His psychiatrists tell me they agree he is disabled and have provided information on him to the Social Security Agency, but a week ago, we got a letter from Social Security denying him disability. How could this happen? What can we do?

Response:

- Social Security usually does not grant disability on first application. Almost no matter how airtight the application is, the first application for disability is usually denied. As of 2008, the denial rate on first application was 69 percent. After denial, the applicant must submit a written signed request for an appeal/reconsideration within 65 days from receipt of the denial letter. In many cases like your son's, disability is granted on appeal/reconsideration. As of 2008, the success rate on first reconsideration was 9 percent and 56 percent were approved following a hearing.
- If the appeal/reconsideration is not successful, the local Social Security office will provide guidance. In Johnson County, the Social Security office is on the second floor of the main Post Office building, at 400 South Clinton Street, Iowa City 52240. The phone number is (319.338.9461). The national Social Security website is: www.socialsecurity.gov.
- The Iowa Legal Aid or the Yellow Pages under Attorneys and Social Security Law can help you find a lawyer from the Private Bar who specialize in appeals.

How does the appeal process work?

- You may wish to have a lawyer when you appeal, but you do not have to pay the lawyer directly. If the appeal/reconsideration is successful, the lawyer is paid by Social Security out

of the back Social Security payments due the person. The back payments go back to when the appeal/reconsideration was filed.

- For example, if the appeal/reconsideration is successful, your son will get back payments back to the time he first applied for disability. Social Security pays the lawyer 25 percent of these back benefits or up to a maximum of \$6,000, whichever one is less.
- If you get a denial of disability on appeal, the letter will state why it was denied.
- Usually this means you have to go back to the psychiatrist or physician to get more information to show that the reason given was incorrect.
- Also, if there have been any service providers, such as Hillcrest, Goodwill, or the Community Mental Health Center, that have worked with your son, they can provide useful information on how he functions on a daily basis and what kind of assistance he needs.
- Often the reason given for the denial is just that the information provided was inadequate or incomplete.
- You need to talk to your lawyer and help him or her get the missing information from the psychiatrists, physicians, and service providers to use in the appeal.
- An appeal can take three months or more. If it is not successful, a hearing will be necessary with an administrative law judge.
- Also, your son may be eligible for SSI (Supplemental Security Income). This program is separate from Social Security Disability. SSI could provide a second monthly payment for your son.
- To determine if he is eligible, call the local Social Security office and make an appointment for yourself and your son.
- When an individual applies for Social Security benefits, Social Security determines the benefit for which the person is eligible.
- The options include Social Security Disability on one's own account, Social Security Disability benefits on a disabled, retired, or deceased parent's account, or SSI benefits.
- Social Security Disability monthly benefits vary depending on the individual's work history. The SSI benefit is set at the maximum amount for which the individual is eligible. If the Social Security Disability payment is small, the individual may be eligible in addition for SSI. When you go in, make sure you or your son have all the financial and other information on your son that might be needed for these determinations. You should call ahead and find out what information is needed.

Scenario 31. My daughter is on Social Security Disability (SSDI) because of her mental illness, but she does have a part time job. She does not get SSI benefits. In fact, the Social Security people say that they encourage people on disability to work. I am afraid that if she makes too much money, they will cut off her disability. I know this can happen because I have heard about it happening to people. I would like to make sure this doesn't happen, but I don't know what to do.

Response: Your daughter may be able to earn more than you think without losing her benefits.

- The Social Security Agency wants to encourage people on disability to work and earn, because work supports people's sense of self-esteem and because some people who work eventually go off disability.
- Social Security now has a program that allows people on disability to earn up to approximately \$12,500 a year without any loss of disability benefits.
- If their income climbs above this figure, they lose their disability benefit, at least temporarily.
- The amount you can earn without loss of benefits depends on whether you receive SSI or SSDI or both. In your case, you have specified that your daughter does not receive SSI, so that is not a factor.

- In addition, you can work full time and go off of SSI and SSDI and still maintain your medical benefits through Social Security.
- There is a charge to keep the medical coverage, but with the cost of prescriptions these days, the cost is well worth it. There is still a limit on what you can have in savings.
- Call your local Social Security office and make an appointment to discuss this. The phone number in Johnson County is (338-9461). The Social Security office is on the second floor of the main Post Office building at 400 S. Clinton Street in Iowa City. An employee there will explain this program and others to you in detail.

Scenario 32. My 30 year old mentally ill son cannot hold a job and is on Social Security Disability. The disability payment helps, but it is not enough for him to afford health care insurance. He really needs to get on Medicaid, but I have no idea how to do that. Can you tell me how to go about this? What do you have to do?

Response: The Department of Human Services office that handles health care issues is located in the Johnson County Health and Human Services Building, 855 S. Dubuque St., Suite 102, Iowa City, IA 52240. The phone number is (319.356.6050).

- After you call and set up an appointment, you will meet with an Income Maintenance employee who will help you complete an application and determine for what programs your son meets the eligibility requirements.
- When you call the office to make the appointment, ask them what information you will need to bring for the application. These application materials are also on line at www.dhs.state.ia.us.
- From the information you give, your son is probably eligible for Medicaid; however, in Iowa there are several different Medicaid programs. The Income Maintenance employees in the Department of Human Services will determine for which of these programs your son is eligible. If he is eligible for more than one program, select the one most beneficial to him.
- Also, you should look into the possibility that your son may be eligible for SSI (Supplemental Security Income). This program is separate from Social Security Disability. SSI could provide a second monthly payment for your son. To determine if he is eligible, call the local Social Security office and make an appointment for yourself and your son.
- When an individual applies for Social Security benefits, Social Security determines for what benefits the person is eligible. The options include Social Security Disability on one's own account, Social Security Disability benefits on a disabled, retired, or deceased parent, or SSI benefits.
- Social Security monthly benefits vary depending on the individual's work history. The SSI benefit is set at the maximum amount for which the individual is eligible. If the Social Security Disability payment is small, the individual may be eligible for SSI.
- When you go in, make sure you or your son have all the financial and other information on your son that might be needed for these determinations. You should call ahead and find out what information is needed.

Family Member Guilt Feelings and Other Emotions

Scenario 33. Our son has been in and out of mental hospitals numerous times. He does recover, but later he has another episode. We were against his moving to another state, over 1000 miles away, but he did anyway. Since he has been there, he has been hospitalized several times. The first couple of times, we flew there and visited him, but he was so sick, he did not appreciate it. In fact, he was hostile. Since then, when he is hospitalized, we call him on the

phone (when he will agree to talk to us) and talk to his hospital psychiatrist and social worker. (He usually gives permission for this). Doing this, rather than going there, seems like the sensible thing to do, but we do feel pretty guilty about it. What do other people in this situation do? What advice can you give?

Response: There is no reason for you and your spouse to feel guilty.

- It is not unusual for people experiencing a psychotic episode to be hostile toward their loved ones.
- After they have recovered, they commonly apologize for the hostile attitude they had and for any disparaging things they said or false charges they made while in the midst of their breakdown.
- Your son did agree to let you visit him in the hospital, even though he was hostile. Often the patient will not allow family members, no matter how concerned they are, to see them.
- Unless you have assurances by phone from your son that he wants you to visit and appreciates your concern, there is no reason for you and your spouse to spend the time and money to fly out to see him. That would be very stressful to you and would do him no good.
- Remember, he is under the care of mental health professionals—psychiatrists, psychologists, social workers, etc. He is getting the care he needs.
- Also, when you get there and he refuses to see you or agrees to but is very hostile and accusatory, the whole experience might make you hostile and resentful towards him, and this could make an already stressful relationship worse.
- The most important thing you can do for your son is to provide the psychiatrists and social workers at the hospital with complete information about your son, his illness, and his history.
 - You should provide the hospital doctors and the social worker with information on your son—on his health history, background, employment, education, etc.
 - Provide them with the name and phone number of his psychiatrist and/or psychologist.
 - If your son has had previous mental breakdowns, you should give them the dates of the previous breakdowns, the hospitals he was in, and (if you have them) the names and phone numbers of the psychiatrists who treated him and the social worker involved.
 - If you know, you can tell them what meds he is on and what the dosages are and what the diagnosis is.
 - This sort of information can greatly improve the treatment your son can be given.
- Because of privacy laws, the hospital personnel may not be allowed to give you information about your son's condition. They can if he signs a release, but he may not do that. Even so, you can still give the hospital personal information about your son. The hospital personnel will be glad to get this information, because it will aid in understanding your son's case and help to get him the best treatment.
- In fact, since your son has had multiple breakdowns, you should have all this information written down in advance. It should be kept up to date and preferably kept in electronic form, so you can quickly e-mail it to the hospital. This will help your son much more than would a refused visit.

See the discussion in the introduction to this document on the need to begin planning while your son is in the hospital for what will happen when he is discharged. This sort of planning is very important.

Scenario 34. Our son is a wonderful person to be around when he is well—smart, articulate, warm, and a good conversationalist. But when he is sick, you wouldn't believe the horrible accusations he makes against me and my husband. He vehemently screams that we

—neglected and—abused him when he was a kid. He says we starved him and did all sorts of horrible, cruel things, none of which happened. (He also accused us of being part of a plot to assassinate President Bush!) Three weeks or so later when he is recovering, he does apologize for these accusations and says he knows they are not true and doesn't know why he said them. (He does remember saying them). Every time we think about it, we feel angry and resentful that he would make such accusations. I do especially, but we also feel guilty about feeling angry and resentful. What should we do?

Response: Many features of your son's case are common.

- It is not unusual for people during a mental breakdown to be hostile and paranoid—and to level horrendous accusations against their loved ones and others.
- The fact that he remembers them is also not unusual, and his apologizing later in recovery for having said them is also common.
- You just have to realize that when your son makes these horrible accusations, he is under the influence of his psychiatric disorder and is not responsible for what he is saying or thinking.
- When this happens, you have to repeatedly remind yourself that it is not your—real son saying these things and that he really does not believe them—or won't soon when he is in recovery.
- Also, remind yourself that you will be getting an apology from him soon.

Dealing with this is a very difficult task. It is natural to respond with anger when someone, even a child of yours, attacks you with outrageous false accusations. The advice given here can help you to deal with this.

Scenario 35. I know people are blaming me for the mental problems my daughter is having. It gets back to me that they have been saying I must really have been a bad mother or this would not have happened. They feel I didn't raise her right. I don't want to let this make me feel guilty, but it does. I have looked back over the years; maybe there are some things I could have done differently; but really, she was treated like my other kids as far as I can remember. What should I do?

Response:

- Your daughter's mental illness is not your fault.
- Mental illness is a biological brain disease. The causes are not yet completely understood, but they are both genetic and environmental.
- Mental illness is not the result of poor upbringing, personal weakness or lack of character.
- No one is to blame for mental illness. These facts are gradually becoming better known among people in general, but not all people are aware of them yet.

People who make comments like those you heard are unaware of the research results of the last 30 years. In the 1950's and 1960's, many psychiatrists and psychologists did believe the theory that mental illness was caused by negligent parenting. For example, this theory stated that cold and unaffectionate mothers were the cause of schizophrenia. This theory was discredited in the 1970s and 1980s, when it was found that the main causal factor in mental illness was genetic propensities. Of course, parents have no control over which of their genes a child gets, so there can be no reason for guilt. As a result of these false theories, many parents (especially mothers) bore a horrible, but completely unjustified burden of guilt, and were condemned by others in addition. This scenario shows how an erroneous—scientific theory can cause untold human suffering. There is no basis for your feelings of guilt today.

A major purpose of the National Alliance on Mental Illness is to educate people in order to rid their minds of false beliefs from the past. Our local affiliate, the National Alliance on Mental

Illness of Johnson County (NAMI-JC) also contributes to this effort. The monthly NAMI-JC meeting is held on the third Wednesday of each month at 6:30 p.m. in the Level 1 conference room at Mercy Hospital. NAMI-JC welcomes members of the public to these meetings and is always seeking new members. The more successful we are in the task of education, the faster we will be able to remove false beliefs like this from people's minds which contribute to the stigmatization of people with mental illnesses and their relatives. For more information, call NAMI-JC at 337-5400. Also, check the national NAMI website (www.nami.org), the state of Iowa NAMI website (www.namiiowa.edu), and the local Johnson County website (www.namijc.org). You should inform those who criticize you of these facts and you can use the information provided by these sources to do that. Education is critically important in overcoming false information about mental illness.

End of Scenarios

Recommended Reading

Crazy in America: The Hidden Tragedy of our Criminalized Mentally Ill, by Mary Beth Pfeifer, 2007

Crazy: A Father's Search Through Our Mental Health System, by Pete Earley.

NOTE: These and other books are available in the library at the NAMI-JC office.

Helpful Resources

National Alliance on Mental Illness – Johnson County: www.namijc.org

National Alliance on Mental Illness: www.nami.org

Mental Health America: www.mentalhealthamerica.net

National Council for Community Behavioral Healthcare: www.TheNationalCouncil.org

National Empowerment Center: www.power2u.org

MoodGYM: <http://moodgym.anu.edu.au>

Suicide Prevention Resource Center: www.sprc.org

National Association for Research on Schizophrenia and Depression: www.narsad.org

Recovery, Inc.: www.recovery-inc.com

Anxiety Disorders Resource Center: www.anxietypanicattack.com

E-couch: <http://ecouch.anu.edu.au> – information on emotional problems

Pendulum: www.pendulum.org – information in bipolar disorder

Schizophrenia.com: www.schizophrenia.com

Substance Abuse and Mental Health Services Administration: www.samhsa.gov

National Institute on Drug Abuse: www.nida.nih.gov

National Institute on Alcohol Abuse and Alcoholism: www.niaaa.nih.gov

Help Lines:

American Psychiatric Association Answer Center: 1-888-35-PSYC (77924) American Psychological Association Public Education Line: 1-800-964-2000

National Suicide Prevention Lifeline: 1-800-273-TALK (8255)

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