Successful Advocacy Techniques for Families

A Workshop for Families and Professionals

Proven tools for accessing mental health services
and for family healing

Successful Advocacy Techniques for Families created by Jane Cartmell
Advocacy Works • P.O. Box 11631, Bainbridge Island, WA 98110 • email: jcartmell@advocacyworks.org
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Workshop presented by Jane Cartmell

Jane Cartmell B.S.W. received her training in Social Work from Washington State University. She has served as President of NAMI-North Coastal San Diego and as Chair of the San Diego County's Sibling and Adult Children's Group. Jane presents workshops for family members and professionals and has presented at Consumer's Conferences, NAMI-California Conference and the National American Psychiatric Association Conference. Her article "In Pursuit of Treatment" is the story of advocacy for her brother and can be found in the Sibling issue of the CAMI Journal. Jane teaches the NAMI Family to Family Education Course on Bainbridge Island where she lives with her husband.

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Preface

Thank you for interceding on behalf of your relative or friend who has a serious brain disorder. By being willing to be involved in this way you are helping your loved one as well as, yourself, your family, and your community.

As a trained Social Worker, I decided that if I was having trouble getting at those resources, I could not imagine how other family members were coping.

Nine years ago when I began advocating for my brother, who I love dearly, and who happens to have paranoid schizophrenia, I found myself in a predicament. He was entering an institutional system where he would finally receive treatment, or so I thought. What I found out was that the resources (albeit sparse) were there, but the reality was that the services were not automatically offered. I would have to learn how to access them on behalf of my brother.

Without professional evaluation there is no diagnosis. Without diagnosis there is no possibility of treatment. Without patient cooperation there is no treatment. Without personal release there is no sharing of information. Without treatment and support, there is little opportunity for recovery.

As a trained social worker I decided that if I was having trouble getting at those resources, I could not imagine how other family members were coping. In 1992 I began a volunteer project to educate family advocates after listening to story after story about problems accessing services.

I would like to thank all of the family members and professionals who have contributed to my own understanding of Advocacy. My membership in the California and Washington State Alliances for the Mentally Ill has brought many friendships into my life. In our own family, I continue to see healing and recovery nine years after my brother's diagnosis. Seeing him today enjoying special family get-togethers with his children and grandchildren gives all of us happiness and peace. This illness has brought sadness of course, but also many gifts.

Our mother passed away long before my brother was diagnosed. She endured many years of his undiagnosed illness not knowing what in the world was wrong. Wouldn't she be happy to know that after all this time, we have accomplished many things.

1. We have identified the illness.
2. We have advocated for proper treatment.
3. My brother has accepted treatment and medication.
4. He lives independently and manages his own symptoms.
5. As a family, we have accepted mental illness and developed a balanced perspective.

Introduction

I first realized how important my advocacy was to my brother's treatment, when a psychiatric nurse told me that even though he was almost in a state of constant psychosis, he would get better if I stayed interested and involved. I believed her and took a risk.

You have chosen to read this manual on the subject of advocacy for a very special reason. You have the courage to make the decision to intercede on behalf of a person who has a serious mental illness. This choice that you have made is a very brave one. Advocacy will bring many challenges and at times can be frustrating. I first realized how important my advocacy was to my brother's treatment when a psychiatric nurse told me that even though he was almost in a state of constant psychosis, he would get better if I stayed interested and involved. I took a risk and believed her. Now almost ten years later, my brother is managing his illness and staying well. He is with us again. What a payoff! I understand that every family's situation is unique. However, I believe in the value of family advocacy because of all the positive changes and wonderful results that I have seen.

The first rule of advocacy is to be sure to take good care of yourself while you engage in this work. It requires clarity of thought, a positive attitude, and all the energy you can muster. It takes time and patience. You will not see immediate results, but over the long haul, if you and your loved one are clear about the goals you have set, you will see steady progress.

So let's get started. I will begin by briefly mentioning some of the topics we will be covering in this manual. We will investigate the problems advocates face and how to overcome them successfully. We will discuss the importance of assessment, and how crucial it is to recognize obstacles. Then we will organize and develop strategies before we actually begin to advocate. Our credibility as an advocate will stand us in good stead long-term.

We will review the art of letter writing. Your skill as an effective writer will be one of your most effective tools. Only you can properly document the advocacy work that you are doing. We will examine the kind of information professionals need, and how

to provide it in a format that is easy for them to understand. These confidential documents that allow us to share our own family perspective about our ill relative are referred to in the manual as the "Historical Chronology" and the "Client Profile".

In our under-funded mental health care system, your perspective is important and your position as a resource in your relative's treatment planning is essential.

Definitions

ADVOCACY: to intercede on behalf of another.

LEVERAGE: a means of exerting pressure in order to accomplish something.

TRUST: to have trust or confidence in to rely on, to believe. To allow to be somewhere or do something without fear of consequences.

How can we possibly advocate for someone without trusting them? The person who is being advocated for needs to trust that their wishes are included in any planning that is done for them.

Recognize the leverage that you possess as a family member. Only you have the opportunity to look at their situation from a historical perspective. You have known your relative longer and usually better than anyone. You have shared their dreams and goals as well as their problems. In our under-funded mental health care system, your perspective is important and your position as a resource in your relative's treatment planning is essential.

We will be advocating in a mental health service delivery system which traditionally has not requested family input. In fact many professionals are still transitioning from the belief that the family has been a part of the patient's problem, to viewing family concern and involvement in recovery, as a benefit to the patient and the therapy.

Chronic/Serious Mental Illness

The problems of the mentally ill and their families are compounded by stigma, one of the cruelest and most prevalent forms of bigotry that exists.

I. Who are the victims?

... individuals who through no fault of their own or their families, suffer from one of several diseases affecting the brain, the most complex of human organs. The causes of such diseases remain unknown, but are probably multiple. There is no cure, but we do have effective treatment for most of them. In addition to having **a** brain disease, people with serious mental illness are (by definition) significantly functionally impaired by the illness for an indefinite period of time (diagnosis, disability, duration). Roughly 1% of the population are seriously mentally ill. The problems of the mentally ill and their families are compounded by stigma, one of the cruelest and most prevalent forms of bigotry that exists.

II. Symptoms of Chronic/Serious Mental Illness:

A. Acute, "positive" symptoms.

1. Distorted perceptions; loss of contact with reality; breakdown of "ego boundaries."

   a. Delusions.

   b. Hallucinations.

2. Disordered, disorganized and confused thinking.
3. Unstable and inappropriate emotions.
4. Bizarre behavior; impaired judgment.

B. Residual ("negative") or deficit symptoms.

1. Vulnerability to certain kinds of stress.
2. Extreme dependency (sometimes combined with hostility).
3. Difficulty with interpersonal relationships.
4. Deficient coping skills.

5. Poor transfer of learning from one situation to another; fear of new situations.
6. Restricted emotional response and lack of enjoyment.
7. Reduced speech and impaired abstract thinking.
8. Reduced ability to pay attention; slowness in performing tasks.
9. Apathy; lack of motivation; phobic avoidance of all situations.
10. Sensitivity to over-stimulation and under stimulation.

III. "Normal' Reactions to Serious Illness:

A. General stress response ("fight, flight, fright").

1. Grief: denial and impatience, (lack of acceptance).
2. Anger and striking out.
3. Guilt and self-blame.
4. Depression: hopeless, helpless feelings, demoralization.
5. Regression to earlier levels of functioning.
6. Preoccupation with "self" (apparent disinterest in others).
7. Interruption of normal development (immaturity).

B. Coping and adaptation:

1. Acceptance and hope: curiosity about the illness and its treatment, and/or efforts to be like everyone else.
2. Responsible patienthood and active collaboration with treatment and rehabilitation.
3. Compensatory changes; life-style modifications (including more realistic goals and expectations).
4. Full participation in life (love and work) .

IV. The bio-psycho-social approach to treatment and rehabilitation:

A. In general, patients require:

1. Individualized treatment.
2. Continuity of care.
3. Patient education about the illness and its treatment (leading to informed consent; responsible patient role).
4. Safe and comfortable surroundings with adequate privacy and contact with others.
5. Contingency plans for crises (to avoid walking on eggshells).
6. Involvement, support, and education of family and/or significant others (with elimination of guilt!).
7. An approach which identifies and builds on strengths.
8. Outreach — help provided in natural settings.
9. A gradual, realistic, step-wise, long term approach.
10. To deal constructively and positively with stigma.

B. Biological needs:

1. Psychiatric care with appropriate medication by a physician and treatment team who understands the illness and its treatment.
   a. Careful monitoring of intended effects and side effects.
   b. Identification of new physical and mental/emotional problems as they emerge.
   c. Attention to both acute (positive) and deficit (negative) symptoms.
2. Elimination of toxic chemicals and unnecessary drugs (alcohol, caffeine, marijuana, "cold" medicine, etc.).

3. Early Detection of danger signals — symptom monitoring by patient and others.
4. Adequate rest and regular planned aerobic exercise.
5. A balanced, nutritional diet.

C. **Psychological Needs:**

1. A therapeutic alliance with a person (or team) which involves support, respect, and reality orientation.
2. Dealing with "normal" reactions to serious illness.
3. Being busy.
   a. A balance between over-stimulation and under-stimulation.
   b. A relaxed (non- rat race) atmosphere.
   c. A regular daily routine.
4. Substitution of responsible adult behavior for inappropriate behavior (behavioral approach).
5. Minimization of handicap; emphasis on strengths; independence as tolerated.

D. **Social Needs:**

1. Learning survival skills; psychosocial and occupational rehabilitation.
2. Communication and problem solving skills for patient and significant others.
3. Construction of a supportive social network. Prevent or reverse social breakdown syndrome.

Charles R. Goldman, M.D. (7/2/90)

Chapter 1
From the Client Perspective

DAVID

On the streets for eighteen years —
Where can he be?
Under bushes, lying in the sun, sitting on a step?
Food: a constant search
Trash barrels, gutters, handouts.

David doesn't say much
When recognized, he only smiles.
His bedroom, a clump of Indian hawthorne
Near the delivery dock of Goodwill Industries.
The bushes are littered with trash,
Remains of past delights.

I wish he would come with me.
I want him to share the comforts of life I have.
David, why are the streets more hospitable
Than the warmth of your mother's home
And the friendship I offer?

By Dan Reese

I am honored to present this section which I feel is the most profound part of the manual. The poem on the preceding page and the following piece was written by Dan Reese who was highly respected in the San Diego mental health community. He received the "Mental Health Person or the Year" award in 1993. All the while Dan suffered through a barrage of symptoms which his psychiatrist diagnosed as a disabling combination of schizo-affective and bi-polar illness. For a period, Dan was able to take clozaril (an a-typical medication) which allowed him some freedom from his symptoms. During this time he was active on many boards and committees. He wrote a grant for and founded a clubhouse for clients in San Diego. He accomplished many projects. The San Diego Mental Health Community will never forget him. Dan died in 1995. I was fortunate to call him my friend.

Let us then approach our advocacy with the utmost respect for the person we care for while being vigilant regarding their needs and wishes.

Dan wrote these two pieces about our mutual friend David. David was homeless, on the streets, ill with schizophrenia over 20 years after serving in Viet Nam. He now lives in his own apartment, but still takes off and lives on the streets for indeterminate periods.

The complex question of how much and when to intervene in our family member's lives is eloquently illustrated for us through Dan's writing. Let us then approach our advocacy with the utmost respect for the person we care for while being vigilant regarding their needs and wishes.

By Dan Reese, 1992

When I think of David, I think of his smile and the long walks we used to take on the beach. He never said much. When we talked, it was about the weather or TV. I never asked him about his time in Vietnam or his years on the streets after he got back. It would have felt like I was intruding into a part of his past he did not wish to share with me. But I knew that even in the silence, we hit it off. After our walks, we'd go to his mother's house for dinner, and then we'd watch TV. It was a happy time for me.

And then, after three and a half years of making good progress David became absorbed in the news of the pending Gulf War. It was all around us, dominating the screen day and night. Three days before war was declared, he left without saying good-bye.

While his mother recovered from a broken hip, I went out in search of him and found him in Balboa Park. We spent time together sitting in the sun and sometimes talking. I felt sad that I couldn't make him budge, and anxious when I had to tell his mother that I couldn't persuade him to go home. She understood. I returned to the same place, and for a time, he was there. He'd drink the Pepsi I'd bring and I'd give him $10 from his mother. I'd try to convince him to go home, but he'd say he "needed a vacation," or that he "didn't feel like it right now."

At first I was eager, but after several visits with him in the park, I realized he wasn't ready to return home. He was a causality of two wars. Finally I learned to tune in to where he was and not try to change him. I knew that as soon as I left, he'd spend the food money I'd given him to buy cigarettes. Then, once again, he'd have to scavenge trash barrels for food.

Why, I often wondered, did that way of life seem so natural for him? Why did he feel so at home on the streets? But I never got an answer. Once again, he disappeared into the anonymity of being homeless and wandering the canyons, parks, and streets of San Diego.

David ... When will you decide to come home again? I can't forget the last time I saw you and the grin on your face when you said, "don't worry, I'll be back!" I believed you. I still believe you and look forward to resuming our walks on the beach.

Chapter 2

A Psychiatrist's Point of View

Tom Henley M.D. has been a community mental health clinic psychiatrist for the last twenty years in north San Diego county. He exemplifies the model of a compassionate, family oriented practitioner.

Tom Henley M.D. was a community mental health clinic psychiatrist for twenty years in north San Diego county. He exemplifies the model of a compassionate, family oriented practitioner. At his retirement, the San Diego Mental Health Consumer Council which includes all the directors, chairs, and presidents of the San Diego client and family organizations, wrote him a letter. I have included part of it here.

"We can never fully express our appreciation for the insight, sensitivity and dedication to mental health clients which has hallmarked your years with County Mental Health. You are probably not aware of your contribution to healing so many lives. Your long history of direct involvement with and support of AMI (Alliance for the Mentally Ill) (where too often others have declined to take part), have been a major contribution in the ability of AMI families to help themselves and to support clients. Your willingness to quietly go the extra mile is one of your qualities we most cherish. We have indeed been fortunate to have you as the model of what professionals could accomplish when they see beyond the "job."

I had the opportunity to ask Dr. Henley to comment about three issues concerning mental health care and treatment and he kindly agreed to contribute his thoughts. The following remarks and stories were his response to these questions:

1. What are the client's, family's, and mental health professional's challenges concerning the issue of confidentiality?
2. Is it more helpful to families and clients for professionals to assume the role of consultant, in a collaborative effort, rather that of a therapist?
3. How can professionals best utilize information from family members?

Regarding the State of the Community Mental Health System

Our mental health system has the correct basic concepts of humane and quality treatment, continuum of treatment and care, and assertive community outreach, but it does not have the resources to meet the true need. The real solution is to hire more professional staff and others to treat and care for the clients/patients and their caregivers. Many excellent mental health professionals would work in the system if the rewards were better, if they knew there would be enough staff to work with to reasonably share the burden.

In my heart of hearts, I believe that if the client and family are properly interviewed and encouraged to communicate with each other and the professional in a supportive atmosphere, there need be no fear of lawsuits.

Regarding Confidentiality and the Mental Health Professional

Professionals are not paid to work with families, and in the professional's constant state of overwhelm, accompanied by a lack of service dollars, for most professionals to even consider including families appears to be especially burdensome. Confidentiality can be a good shield to prevent the additional work of communicating with families.

The fear of lawsuits in our litigious society is a common fear of the mental health professional, including doctors. We hear stories of a professional being sued supposedly for breaching confidentiality. In my twenty plus years of working within the public mental health system in California, the only lawsuits I personally have heard of involved a person whose case involved a custody situation or some kind of financial settlement. All of these cases involved a person with a lesser degree of mental illness. In my heart of hearts, I believe that if the client and family are properly interviewed and encouraged to communicate with each other and the professional in a supportive atmosphere, there need be no fear of lawsuits.

Working with the Family

Unfortunately, the popular method of therapy suggests that including the family and patient jointly in the clinical setting is somehow 'out of the norm'. However, if the professional begins with open communication and structures it as routine, the therapist can take care of any future problems by indicating in his/her remarks to the patient at the outset that he/she and the interested family member(s) are both invited to participate. When the patient is seriously chronically mentally ill and needs all the help and support they can get, i.e. living with the family, the professional needs to structure the assessment and interview so it FAVORS INCLUSION of the family. An important benefit that the professional receives as an added value is the family member as a witness to important communications regarding medication, crisis services etc.

Unfortunately, the popular method of therapy suggests that including the family and patient jointly in the clinical setting is somehow 'Out of the norm'.

Case Examples

1. A middle class woman in her thirties came in accompanied by her mother for an initial assessment. The diagnosis was severe personality disorder accompanied by numerous suicide attempts and frequent hospitalizations. She recently lost her private insurance because her husband was divorcing her and taking custody of their children due to her serious mental illness.

When I came to the waiting room and called her, both she and her mother approached. At this moment I introduced myself and explained that we could all speak together or she could come alone. At this time the patient was given the option of not including her mother although here (as is frequently the case) she wanted her mother to be included. This woman, upon separation from her husband and children, moved in with her parents in their middle class home where she is comfortable.

During the interview, the risk of another suicide attempt was discussed with the patient and mother. We talked about crisis resources including an 800 hotline phone number in the county

so that resources were understood. I asked the client "If you need help in a crisis, would you ask for help?" The woman replied, "Yes." The mother was asked, "Do you feel that you could call for help?' and the mother replied affirmatively.

Here the risk of suicide was discussed with the patient and the mother. The mother represents a valuable resource to the system and the family crisis. She understands the resources and at the same time is an important witness to the doctor. 100% of the time a patient this sick will not sue, BUT she may well commit suicide. We as professionals cannot let the overly strict interpretation of confidentiality prevent us from providing good initial assessment to the patient and their family.

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2. A young Mandarin Chinese man came in for an assessment with his sister. He is a member of a family of twelve, recently emigrated, who do not yet speak English. They are not very familiar with the culture here. His sister acted as an interpreter. She is the only person in her family who speaks English.

This man was diagnosed with paranoid schizophrenia. In the past he has had violent outbursts, but with medication he has calmed down extremely well. His family is still wary of him and refers to him as "lazy." Of course he is not lazy. He is suffering from his symptoms of mental illness as well as his rather high dosage medication. He lives with his family as is very common in their culture, and is usually alone during much of the day. The family wonders, "What do we do about him.?" I advised the sister to begin drawing him out by one of the relatives taking him for a walk around the block every evening when they return from work.

This man is suffering from a high degree of anxiety and wonders what will happen to him for the rest of his life. He needs to be reassured and drawn out. I asked the sister, "What kinds of things did your brother enjoy doing around the house before he became ill?" She replied, "He was good at doing the dishes." I recommended to her that he do part of the dishes every night with another family member.

Family and Client Relationship

Unfortunately most social workers still possess in-grained prejudices. Their fundamental direction seems to continue to be to the detriment of the ill individual and their family, to get the client away from the family. I hear over and over again by experienced as well as new social workers, "Parents should back off and let them make more of their own decisions. They should live more independently."

We must begin to view the role and speciality of the mental health professionals as a consultant to the family rather than therapist.

I ask you, "Why act as if it's a psycho-social problem if a patient wants to live with their middle class family rather than in a less desirable board and care? Why do we as professionals consider it our therapeutic right to impose our own view into these family situations?" We must begin to view the role and speciality of the mental health professionals as a consultant to the family rather than therapist.

Important Points for Professionals Working with Families

I. History:

Professionals are still transitioning from seeing parents (families) as part of a patient's problem to seeing them at least as a source of benefit to the patient and the therapy if not a resource for the patient. Professionals have come part of the way, but still need to go further.

II. Spectrum of Mental Illness:

Professionals need to distinguish between the needs of patients severely disabled by mental illness usually through "psychosis," and other patients with mental health problems.

III. Professionals' Care of the Severely Disabled Mentally Ill:

A. Work around confidentiality. Do not hide behind it.

B. Seek history from families by asking for written statements if not an actual face to face meeting.

C. Educate families by being a consultant to them while a therapist to the patient.

D. In an under-resourced "Managed" Mental Health Treatment and Care (non) "System", recognize the family's position as the best resource for many severely disabled persons for their housing and the monitoring of their medication. Include them as part of the treatment team without prejudice.

E. Find a way to reconcile with patients who are Psychiatric Survivors and hostile to their families, and yet still in need of their family's support.

IV. Professionals need to change their perceptions, attitudes, and relationships with families.

What sustains me as a psychiatrist is the love and caring that I see the clients and families give to each other. Clients whose beings are ravaged with mental illness reach out to one another selflessly, with understanding and compassion, bestowing precious gifts for which there are no substitutes at any price. Families enduring the grief of the living death of their loved one emotionally wasted by an eternity of pain, raise themselves above it, then turn to lift others up. Gaining strength, they go on to create a nationwide movement that slowly but steadily is bettering all of society.

Professionals need to distinguish between the needs of patients severely disabled by mental illness, (usually through "psychosis",) and other patients with mental health problems.

Role of Families and Professionals

Role of Family Member

Recognize and accept relative's illness. This may involve grieving.

Learn about the treatment plan and ask to be involved in future planning.

Learn advocacy techniques. Get involved in advocacy activities.

Have a plan for what to do when a crisis occurs.

Learn to see relative's behavior as separate from the person. Set limits when necessary.

Build relationships with mental health professionals.

Role of Professional

Respect the family and the client as credible sources of information. Take advantage of their knowledge.

Share information whenever possible - especially regarding treatment planning and everyday management.

Learn from family members what has worked and what has not worked.

Refer families to support groups. Organize and develop groups when possible.

Communicate with other professionals involved in patient's care.

By Susan Lund M.F.C.C.

Chapter 3

Consumer Rights

In America for many reasons, we are less demanding and less discriminating about the quality of many of the products that we buy. Why is accessing mental health treatment so difficult? We will discuss some of the general reasons here.

When we begin the task of evaluation, the first thing we must do is to establish the problems that we are facing.

Why is accessing mental health treatment so difficult? We will discuss some of the general reasons here. Traditionally we have been blessed with such a variety of goods and services, we have been taught that if we do not like one product, we can just choose another brand. Sadly treatments for serious mental illnesses are scarce. We sometimes think we should just accept what is offered without question. This is not so. We must advocate for the services we know are necessary.

The first thing we must do to establish the task of evaluation is to define the problems that we are facing. We know all too well that it is extremely difficult. Here are the reasons why.

1. The facts are hard to determine
2. Rights are hard to define.
3. Problems may change over time.
4. We may not want to acknowledge the problem.

The facts are hard to determine for many different reasons. We are not usually educated about mental illness in our society. How do we determine that the illness is present? If we want to discuss the problem with a professional, we are required to know enough relevant facts to be able to provide concrete evidence that the disease is causing the person to be dangerous to him/herself or others, or causing the person to be gravely disabled before any intervention is considered.

Our rights are hard to define because we often do not know what is legally right. We do know what is morally right. We can be extremely helpful if we understand:

A. What is an ideal diagnostic workup?
B. What are the consumer's and family's rights?

We can be there to provide information by being clear and concise so that an appropriate level of service is achieved.

The problems for us and our relatives change over time, sometimes as often as on a daily basis. No wonder we have difficulty articulating our needs! Managing these illnesses requires a steady flow of information among the patient, the family, and the professionals. Communicating within the family so that we all become more educated about these illnesses is essential.

Managing these illnesses requires a steady flow of information among the patient, the family and the professionals.

We may not want to acknowledge the problem. We have all learned that when these diseases gradually worsen over time, our level of tolerance often deepens too. When we experience the illness becoming more serious, we need to talk about it within our families and with a professional.

Worksheet

Prioritize the Problems

1. Immediate issues we must address –
2. Short-term problems we need to plan for –
3. Long-term supports –
4. Long-term challenges –

Immediate issues we must address are the problems that are causing disruption in our mentally ill loved one's lives, in the family's lives, and sometimes in our communities, who also may be affected.

One example might be that our ill relative does not take their medication consistently. June's son was facing being evicted from his apartment. He was not taking his meds regularly causing him to have delusional thinking which caused many problems. June learned that he could receive his meds on a weekly basis by inoculation. He agreed to do this, and not only feels better but is more stable. He is less inclined to use stimulants, and is beginning to paint his apartment.

1. Describe here your most immediate issue.

_____

_____

_____

2. What are the short-term problems/challenges?

_____

_____

_____

An important fact to mention here is that June actually solved three problems when she addressed the immediate issue of medication compliance with her son. Weekly inoculations solved the medication compliance problem. The stability that her son achieved solved his potential eviction problem. Because he felt better, he could help his mother paint his apartment.

3. List some resources in your home or community that might help you address your issue. If you have trouble thinking of any, is there anyone you know who you could ask for help?

Remember all we can do is one thing at a time. It helps to make a list of what we need to do so that we can put it down on our "To Do" list and stop carrying it around in our head. We will not forget about it but it is "put down" so we don't worry about it unnecessarily.

4. What would you like to "put down" here, or what are the long-term challenges?

Consumer Rights

Developed by:
Bridges Mental Health Ombuds Service
Serving Clallam, Jefferson and Kitsap Counties
(360) 377-8174
(888) 377-8174

1. The Right to Be Treated with Respect and Dignity.
2. The Right to Help Develop a Plan of care and services that meets your needs.
3. The Right to Refuse Any Proposed Treatment.
4. The Right to Receive Care which does not discriminate against you regardless of your race, color, national origin, creed, religion, sex, sexual orientation, age, income, disabled veteran status, Vietnam era status or disability.
5. The Right to be Free of Any Sexual Exploitation or Harassment.
6. The Right to Receive an Explanation of all medications prescribed, including expected effect and possible side effects.
7. The Right to Review Your Care Record.
8. The Right to Confidentiality.
9. The Right to Review the Provider's Grievance Policy.
10. The Right to Lodge a Complaint or grievance with the Ombuds, RSN, or provider if you believe your rights have been violated.
11. The Right to Be Free of Retaliation or the threat of retaliation.

Family Rights

Developed by the San Francisco Alliance for the Mentally Ill in response to requests from family members and mental health providers.

1. The Right to Dignity, Privacy and Humane Treatment.
2. The Right to Information, with consent of family member, including information about the patient's diagnosis, prognosis, medications and their side effects, and the patient's progress.
3. The Right of Next of Kin to be Notified of Hospitalization and or release or transfer unless family member objects.
4. The Right to Provide Information about family member that can be of use to the treatment team.
5. The Right to be Involved as a Part of the Treatment Team with consent of family member.
6. The Right to Continuity of Treatment and a Service Plan for family member.
7. The Right to Guidelines and Policies of the program or facility.
8. The Right to Professional Guidance and Direction in dealing with the complexities of the Mental Health System.
9. The Right of Reasonable Access to family member's Case Manager or other contact person.
10. The Right to Receive Support and/or Information on managing the stress of dealing with a seriously mentally ill family person.

Chapter 4
Legal Structures

Health Care Directives

Power of Attorney

Guardianship

Legal Structures

Basic Information Regarding Legal Structures

The following information is intended to provide general information only. Family members should contact their local bar association for referrals to lawyers with special training and expertise in this area.

The state of Washington has recognized that some people with incapacities cannot exercise their rights or provide for their basic needs without assistance. As family members of persons with brain disorders (mental illness), we recognize that the liberty and autonomy of these people seriously disabled by these disorders, should be restricted only to the extent necessary to adequately provide for their own health or safety, or to adequately manage their financial affairs.

Advocates promoting the independence of persons with disabling mental illness are supportive of the concept that the "state" as represented by the court and/or legal system should only intervene in the person's normal, self chosen life activities, as a last resort. It is also agreed upon by advocates that this intervention is done only to the extent necessary, to meet the identified need.

The options include:

1. Health Care Directives
2. Powers of Attorney
3. Guardianship

The following information will supply a minimum outline regarding these three options. I stress that this is intended to provide general information only. Your local bar association should be contacted for further information for a referral to an attorney in your community.

Health Care Directives

A Health Care Directive gives the legal right to an ill person to refuse medical treatment once he/she is diagnosed as terminally ill.

1. Person must implement while having the capacity to do so.
2. Person must have terminal condition, be in permanent vegetative state, artificially prolonging life.
3. Person directs that life-sustaining treatment be withheld or withdrawn.
4. Person directs family and physicians to honor wishes.
5. Person may direct or refuse artificially provided nutrition and/or hydration.
6. Person may direct organ donation
7. Document must be signed in the presence of a witness.

Powers of Attorney

A Durable Power of Attorney authorizes another to make medical and financial decisions. Three kinds of Power of Attorney exist. The first takes effect immediately, the second has a limited purpose, and the third takes effect only upon the finding of incapacity by a physician or the court.

1. Person must implement while having the capacity to do so.
2. Document can become effective immediately or upon finding of disability (by physical) or incompetence (by a court).
3. As to property and liabilities: Holder of Power of Attorney has complete control over assets and liabilities to use, see or give away without court authority.
4. As to personal/medical/living: Holder of Power of Attorney may consent to medical treatment or choice of housing.

5. Holder of Power of Attorney is not required to account to the court.
6. Power of Attorney can be revoked by the principal (signer) at any time.
7. Principal can also act so that Power of Attorney may not be "protective".
8. Health care provisions may be ignored by physicians if directive does not comply with state law.

Guardianship

Guardianship may be obtained if an incapacity results in the inability to exercise rights or meet basic needs independently.

1. Guardian may be appointed by the Superior Court of the county.
2. Guardian may handle personal and/or financial affairs.
3. Person named may be family member or professional guardian, but court must approve of guardian based upon recommendation of a court-appointed guardian ad litem.
4. Guardianship is subject to annual (or every three year) review by the court for an accounting of manner in which funds have been used i.e. medical, personal, or living expenses for the person.
5. Guardian cannot sell or give away any property without a court order. A separate account must be maintained.
6. An annual report must be presented showing receipts of income and disbursements.
7. Guardian must file an inventory of assets and a proposed budget.
8. Guardian must keep court informed of any changes in living situation.

Chapter 5

Assessment

Assessment requires common sense, good listening skills, and clear vision. We need to be able to evaluate what we are hearing from all the parties involved and develop a plan that is workable for our relative and for us. We all practice the skills necessary for assessment when we set a goal and do our homework to reach it. In this section, we will learn to practice these familiar skills with an emphasis on advocacy.

Assess is defined in the root of the Latin word assessare and assodere, meaning to sit beside, and to act as an assessor. We, as family, are constantly called upon to do this when we guide our siblings into right actions, or when we as parents watch over our young children while teaching them not to be afraid of life.

"He drew a circle that kept me out; heretic, rebel, a thing to flout. But love and I had the wit to win. We drew a circle that took him in."

Edward Markham

Now is the time to embrace and nurture the support that you have in your family. Involve your family members. Ask for their support and constructive input. A dear friend of mine in the family movement advises, "Your well children may not want to help at first, but you should not help them pretend there is no problem. ou can understand your well childrens' reticence, but you cannot afford to buy into it." Her strong advice is to ask everyone in the family to set priorities because they will help you later and you're going to need all the help you can get.

Many well siblings say that they are not informed, and they are left out of the decision making process in their families. Parents often feel that they want to 'protect' the ill child and 'not bother' the well ones. In reality the well siblings usually share the responsibility for their ill brother or sister later in life. Why not start their education about mental illness now and nurture the support they can offer?

Remember that usually the professionals involved in the diagnostic process are new on the scene. Unfortunately, many still maintain a belief that somehow families cause this illness, or at the very least, have neglected to get treatment earlier. They do not know the history of our family or our relative. Usually we are the ones who first recognize deterioration in our loved ones. We must present the history and deterioration of the illness to professionals in terms they understand.

In a survey conducted by Consumer Sciences (CHS) and the National Mental Health Association (NMHA), data was gathered from 1,328 family caregivers and 879 patients. One of their findings indicates that most families wait on average four years to see a doctor after first noticing problems with their child. It may be

true that assessing the signs for serious mental illness is a difficult task for families but one that cannot be ignored, especially now that we know that severe mental illnesses are biologically based brain diseases.

If we are unsure of the steps that we must take next, it is only because we do not have enough information. Contact your local National Alliance for the Mentally Ill (NAMI) National Helpline 1-800-950-6264 or go to www.nami.org. It will provide you with support, education, and names of professionals in your community who work with families. Ask them for a "Symptom Checklist." Become informed about what to look for if you have serious concerns. Read everything that you can get your hands on. Become an expert.

When we create an effective team within our family network and learn to access local community resources, we can use our love and wit to win and draw that circle to take our loved one in.

Dealing with Mental Health Professionals & Facilities

At times any/all people involved with the mentally ill in this country are likely to become frustrated by:

1. Patients who don't improve and/or will not accept treatment.
2. The stigma, ignorance, and mistreatment of the mentally ill.
3. Families who want results (cures) that treaters cannot deliver.
4. The ineffectiveness of our embryonic state of knowledge and treatment of the mentally ill.
5. The lack of adequate funding for programs, staff, and patients' medical and basic needs.

Remember: All professions and facilities have good (competent, sensitive) and bad (incompetent, inconsiderate) people

Facilities and professionals can do little or nothing for people who refuse care or treatment unless they are on conservatorship or a temporary "hold." Then too, they are often quite limited in what they can offer or accomplish. So **KEEP YOUR EXPECTATIONS REALISTIC.**

Confidentiality is an important concern for several reasons:

1. Legalities need to be considered. Consent is a major factor.
2. Professionals will often consider their relationship with your relative as primary, thus will consider the impact that contact with you will have on that relationship.

Professionals in the past were taught that families were part of the problem. Some professionals have only/mostly seen problem parents.

THEREFORE, what you can do to enhance your relationships with professionals and facilities is:

1. Be a courteous consumer.
2. Provide information.
3. Be respectful of their time, pressures, etc.
4. Ask how you can be involved in a supportive way (as you did when your children were in grade school or high school.)
5. Request meetings (with or without your relative present), as the need arises.
6. You may ask for a diagnosis, general treatment plan, medication information, and a prognosis.
7. Expect to be treated respectfully and with consideration.

Rebecca Wollis/Buckelew Houses

Setting Your Goals

What are the goals that your ill relative wants to reach?

If these goals do not seem realistic for today, list some smaller ones that will lead toward them.

Are you communicating within your family (and perhaps your extended family members) about the mental illness? List here how your other family members could help. Be specific.

If your family members are not educated about the illness (and most of us are not), how would you change that if you could?

_____

_____

_____

_____

_____

Are there particular issues that your family members need to talk about within the family and/or with a counselor before goal setting can begin? Make a note of the most important one here.

_____

_____

_____

_____

_____

_____

Ingredients of a Proper Assessment Plan

1. Definition and placement of the current problem.

2. List the specific reason why the person needs help.

3. What support systems or people (energies or vulnerabilities) exist that promote or modify possible approaches to the problem?

4. What strategies can be employed to meet immediate and long range goals?

Source: Theories of Social Casework by Roberts and Nee

Chapter 6
Advocacy

The family members and consumers who can succeed in communicating and working together stop being "Prisoners of Mental Illness." We are in a war folks . . . a fight to hold onto the healthy part of the one we love, a fight to save this person from a terribly debilitating disease.

If we can integrate the information and important insights in this section into our own advocacy, we will benefit, our families will benefit, and professionals and society will benefit.

Advocate:
One who intercedes on behalf of another.

The topic and the scope of advocacy is broad, but we are here to discuss successful methods of working with and interceding on behalf of our loved ones who have serious mental illness. The requirements for this job are numerous and the competition is slim to nothing. The payoff is big. The family members and consumers who can succeed in communicating and working together stop being "Prisoners of Mental Illness." We are in a war folks . . . a fight to hold onto the healthy part of the one we love, a fight to save this person from a terribly debilitating disease.

The first step that we have to take is to ACCEPT THE PERSON THE WAY THEY ARE NOW, NOT THE WAY THEY WERE BEFORE THE ONSET OF THE DISEASE. As we begin the act of advocacy, ask yourself these questions honestly.

What are your goals for your relative?

What are your motives for these goals?

How did you arrive at these goals?

Are these goals the same as the goals of your loved one's?

As the primary advocate for our relative, we are faced with what looks like a barrage of pressures. Our relative may have what looks like an unrealistic idea of what they can achieve. But wait, stop right there and think back. Haven't we all set goals for ourselves that seemed like pie in the sky at sometime in our lives? Yet as we worked toward these goals, we modeled, trimmed, and tailored them to fit our abilities and resources. For instance, during college we may have wanted to go to medical school during our freshman year. We may have found that science was not our strong suit, so we trimmed our goal to another area of the health care field. Everyone who sets goals goes through a similar process. Our job is to help our relatives do the same thing. As their advocate, we must help them to keep their dreams intact in the midst of their fight for recovery.

As we go about our advocacy, we need to be honest with ourselves about our relationship with our relative. We must evaluate what our communication is based on. Ask yourself these questions.

Does my ill relative trust me?

If so, good! If not, why not?

How can you establish trust, and what resources do you need to accomplish that?

...if we have resisted buying into the current system of cultural values that says that everyone has to have their own car, their own place, their own job, their own girl or boy friend, then both you and your relative can begin to evaluate what is realistic.

Be honest with the professional staff you are dealing with.

The importance of loyalty to your mentally ill relative is key. A mother told this story to me about a visit she had with her mentally ill son who is frequently in and out of jail.

As she was getting ready to leave the jail, her son, who usually plays the tough guy role, said softly to her, "You know Ma, a guy here told me that the only people you can really trust are the ones who visit you in prison and the hospital . . . and you're one of those for me."

As you all know, family members who are willing to advocate have a tough road ahead. You must have enough self confidence to be willing to put yourself out there and face disagreement, possibly anger from your relative. Our own motives may be questioned by our relative and the mental health system.

If we have done our homework listening and communicating with our relative about their dreams and goals, if we have accepted them just as they are, if we have resisted buying into the current system of cultural values that says that everyone has to have their own car, their own place, their own job, their own girl or boy friend, then both you and your relative can begin to evaluate what is realistic. We can all choose goals that will be attainable and most importantly support the person in their own recovery.

When we as family members can really accept our loved one and stop wishing that things were different or better or the way they used to be, we can begin the job of living for today.

E. Fuller Torrey M.D. in his book, "Surviving Schizophrenia, A Family Manual", shares a client's remark. "I'm so glad that my mother can finally admit that I'm sick. Now I can work on getting better."

When we as family members can really accept our loved one and stop wishing that things were different or better or the way they used to be, we can begin the job of living for today. Our relative will feel supported and nurtured in a healthy way. We as a family can begin to heal from the traumatic stress that the onset of serious mental illness brings.

Key Notes for Advocates

EFFECTIVE LETTERS

1. Introduction (Start with something positive, if possible.)

Example:

Thank you for your phone call.

My brother seems to be responding better.

We had a good visit last time.

II. State purpose or reason for concern

Be brief and to the point.

III. Establish your personal commitment to be of assistance

Example:

On my last three visits . . .

Give a concrete example of the concern.

IV. State your personal commitment to be of assistance

If I can be of any assistance....

V. Thank the person for their time and attention

PHONE CALLS

Write a list of all the items you want to cover before you dial the phone. Be clear and to the point. Refrain from telling stories: Their time is limited. When issues are covered or an agreement is reached which you feel is important, follow up your phone call with a letter stating the points which you believe were covered.

MENTOR: A PROFESSIONAL WHO TAKES A SPECIAL INTEREST IN YOU

Find a mentor in the system and be nice to them. Ask if you can continue to call them occasionally for advice as you and your relative proceed through the system. (This person can be a tremendous help in guiding you.)

HISTORICAL CHRONOLOGY

Keep a record of important events in your ill relative's life. It is important to continually update the chronology so you do not have to keep telling your stories over and over. (Professionals hear so many stories, sometimes they turn off. Wouldn't you?) A well written historical chronology gives a professional something concrete and improves the family's credibility. They know we mean business!

CHAPTER 7

Documentation: Family Members

Family member's documentation of the illness is important because it provides a context for the history and severity of their relative's illness, especially when a person has been untreated for long periods. The family has usually known the person best, and has been there to see episodes of illness and wellness.

Persons who suffer from serious brain disorders have varying degrees of awareness of their illness. Sometimes the degree of awareness is affected by the symptoms of the disease itself. The issue of awareness is important because it affects a person's ability to seek treatment.

Family member's documentation of the illness is important because it provides a context for the history and severity of their relative's illness especially when a person has been untreated for long periods. The family has usually known the person best and has been there to see episodes of illness and wellness.

"When the patient is in an acute phase and too ill to focus, we must plan for him, but always connecting with him when he is well enough to say what he really wants."

"Welcome Silence"
by Carol North M.D.

When the family shares their experiences with the Mental Health Professional, many good things occur:

1. Reliable information is exchanged about the brain disorder.
2. The family feels acknowledged and validated regarding their experience.
3. The family gains knowledge about the brain disorder.
4. The client receives support.
5. The Mental Health Professional learns what has and what has not worked.
6. The family and ill relative are empowered to support each other

In this section there is an example of a letter from a family member requesting the entire family to share their experiences. Some of the responses are included. Eventually a compilation of the information called a "Historical Chronology" will be written by the family and submitted to Mental Health Professionals.

Letter of Appeal for History

Dear Family Members,

I have a favor to ask of everyone. When I talked to the counselor at the correctional facility, she was very interested in any history that we could give her about Roger. Since he has been detained, he has been unwilling to share anything about himself with the professionals on staff. Of course, this makes it very difficult for them to understand what his problems are.

Since Roger's evaluation period is limited in the Admissions Unit (usually about two months), it is important for us to offer any information to them now, before the evaluation is concluded. Sue and Catherine are both writing a few paragraphs about some experiences that they have had with Roger and I think that it is important for all of us to contribute.

According to the counselor, after this two month period, Roger will appear before a panel of a psychiatrist, a psychologist, and a nurse. They will form a diagnosis, and he will be placed in a particular treatment setting. So, of course, you can see why it is important for us to offer any concerns or thoughts that we have now before the evaluation is completed.

Like I said to the counselor, this experience is a new one for our family. We certainly want the best possible results for Roger during this period of treatment so that he can begin recovery and have a happier life.

I love you all.

Notes from Father

Local Highway Accident

Two years ago this summer, Roger took my car, with my permission, in order to play golf at the local golf course. He came upon a traffic stop at a construction site. When the line of cars started to proceed, a deputy sheriff acting as the flagman waved him to stop because he noticed that my son was slumped over in the car while he was in line. He did not stop and when a construction worker stepped out waving for him to stop, Roger hit him and knocked him up on the hood of the car. The man was not seriously hurt, but easily could have been.

When Roger was forced to stop by an obstacle in the road, he refused to get out of the car and actually locked himself in the car. Later, the police had to force the door open and lift him out of the car in order to take him to jail. He maintained he was harassed by the police. I had to pay for the towing to get my car back. In discussing the incident, my son did not seem concerned about the injured worker, but only about the problem the police caused him.

Arson Fire (two years later)

The reason Roger set fire to the neighbor's mobile home is difficult to understand. They have been wonderful neighbors to me and it seemed to me that my son got along with them. When I was visiting in California, Roger told them in a threatening manner that something bad was going to happen to them. The next day he set fire to their home while they were gone. The house was destroyed along with irreplaceable personal items and all the contents. He denied knowing anything about the fire, saying he had not been home when it happened. A resident of the park, who was a family friend, later reported seeing Roger at the neighbor's window sprinkling gasoline inside. My son pleaded guilty to the arson when he was apprehended. In recent discussions with family

members, he stated that he committed the crime to save his life. He claimed the neighbors were causing him to suffer from chemicals which they released and these affected him. Shortly after the fire, he went to his brother's house nearby where he spoke incoherently and appeared to be in terrible condition. He would not rest or eat anything, but left and told us later that he went to the county jail to serve time on his conviction for failure to stop for the sheriff.

Tough Love Meeting

Before we knew that Roger had set the arson fire, in our continuing efforts to persuade him to accept treatment for his mental illness, we discussed his situation with several mental health professionals. After considerable planning, and on the advice of a psychologist, his brother, three sisters and I had a "tough love" talk with him. We told him that unless he was willing to seek help, we would not allow him to continue to stay at my home.

His reaction was that we were the ones who needed help, and he was fine. He left my home immediately, and we later found that he had gone to a friend's home in a nearby city. The friend told his parents that Roger talked "crazy" at night with him. The friend's father told me that Roger appeared to be in serious need of treatment. The family had no room for Roger, and after a few days, they took him downtown because their son was leaving. Roger wanted to buy a ticket to California although he had very little money with him.

When he could not buy the ticket to California he somehow got to a small town, about twenty miles away. After dark, he called his aunt in California saying he was cold and hungry and asked for money. She sent him some money, and he called me at midnight a day later from a neighboring state. He went to his uncle's home where the police picked him up. Another disturbing incident occurred on the way to the bus depot. Roger told me that he would give me a dollar if I ran over a certain pedestrian.

No Place to Go

We have been talking to Roger about what he plans to do when he is released. He says he would like to see his children. He has refused to let the two older ones visit him in prison as he did not want them to see him there. None of them are in a position to be of any help to him. His son is just married and is in the service. His daughter is unmarried and lives with two other girls. The youngest daughter is high school age and lives with her mother. Roger says he will get a job but he is not sure what it will be. He has not held a job for two years, and when he worked before that, he had serious difficulties getting along with fellow workers. He did the cooking and helped with the yard work when he was with me.

When asked if he couldn't earn some money for things through the incentive program in the prison, he said he has a bad back and cannot work. When he left my place, he had to ask for money from his aunt and stayed with his uncle. Those options will not be available to him now, and he has not shown that he could get along without help. Roger cannot go back to the mobile home park where he stayed with me because he set the adjoining home on fire, and it is for this crime that he is in prison. These neighbors have obtained a restraining order against him. Other residents in the park are very concerned about what he will do when he gets out. The family friend who saw Roger at the crime scene is very concerned about what he might do when he is released. We are also very concerned about his reaction to us, because of our efforts to get him into a treatment facility. We have been told by his counselor that no facility will accept him because of his crime and unmedicated condition.

Feeling About Him

Our family is very concerned about what the immediate future holds for Roger. Because of the difficulty he has in getting along with people, we feel he most certainly will get into a situation

where he will think someone is trying to harm him, and he will take action against that person. Or he will by his words and/or actions cause someone to injure him. Without medication we cannot imagine how he could hold a job, and take care of himself. We have done everything we can think of to persuade him to begin medication, but he says he will think it over. He has always resisted our efforts to get him to the dentist, optometrist or physician, and has refused to take any medication, even an aspirin. He can give us no real reason why he should not take the medication which has been prescribed for him. His condition has gotten progressively worse for some time.

He was at one time able to work and support himself. He has alienated his former friends and people avoid him because of his manner and suspicious nature. He has told us of the voices he hears on a continuous basis as well as the smells he is aware of. He now thinks that satellites are after him. His solution seems to be that if he is patient, all of this will go away. When his older brother read this, he remembered that Roger had attempted a small job for a friend while I was in California. He could not make decisions about the work, so he needed to have a lot of ordinary decisions made for him.

Notes from Youngest Sister

My involvement with Roger has been sporadic throughout my lifetime. Because there is such a wide age difference between us, we haven't been very close.

I have lived in the San Diego area for almost three years. When I moved down, I left all my belongings in the Northwest.

My first solid indication that Roger was mentally ill occurred almost three years ago when John, a friend of mine in Seattle, agreed to help move my things down to California for me. At that time, all of my belongings were in storage in a small town in western Washington. John had agreed to take part of his vacation to drive my car down with a U Haul attached with my belongings. I had asked Roger, who was living with my father, if he would be willing to help my friend move some of the heavier items. Roger said no, he would not. I took that at face value and did not expect him to help. When John arrived at the storage unit, Roger was there. From here on out my friend has recounted the events to me.

John told me that, right off the bat, Roger was belligerent toward him. Roger would shove John when John would walk by him. Roger would merely shrug his shoulders and look at John like he didn't know what he was doing. The whole time Roger was yelling profanities at John. This continued for some time until Roger started spitting on John's feet. John told him to stop but Roger didn't. At one point Roger was on one end of a piece of furniture and John was on the other. Roger shoved the furniture, pinning John against the wall. John told me at this time he was afraid for his safety. After Roger let John go, John got into the moving van to arrange something and Roger locked him inside. My friend started yelling at Roger until he finally let him out. Several other incidents happened until John finally called the management to have Roger removed from the premises; which is what happened.

Nothing serious happened to my friend but it took him about a year to tell me about this incident. John was really disturbed about what happened, but he was afraid to tell me that he thought Roger was mentally ill, because he didn't know if I knew.

Notes from Oldest Child – Age 25

January 1988

My sister Kim, brother Bobby and I went to visit our father. I hadn't seen him in over a year. We all started talking – Dad interrupted and started telling us about a "punk" boy on Capital Peak (a peak in Olympia) who was bothering him. Dad said he was going to beat the shit out of him. We all just sat there as he talked. I think we were all too afraid to say anything. He continued to talk of this incident then when he stopped we changed the conversation to what to have for dinner. About two hours later he interrupted our conversation to say that he was just joking about that punk boy. I thought it was very weird to say that but we just ignored it and went on. The same night we had to go out to get dinner. I didn't feel comfortable leaving Bobby or Kim with Dad so I sent them out to get dinner. While they were gone Dad started telling me that someone was trying to kill him and had been for a long time. He said that they tried to gas him at the house. He used celebrity names – Hugh Heffner, etc. He looked like he really believed what he was saying and he looked scared.

December 1988

Bobby and Dad went to cut down a Christmas tree in the forest. Dad started talking about people wanting to kill him using celebrity names. Bobby remembers him looking different and Bobby was very scared. "He didn't know what Dad was going to do."

Chapter 8
Documentation: The Client

Historical Chronology

Client Profile

The creation of the **Historical Chronology** must be approached with respect for the individual who is ill.

The Historical Chronology is a compilation of factual concrete information regarding your ill relative. The entire document should be no longer than two neatly typed pages. If possible, it should contain a well rounded perspective of the family's experience of their relative's serious mental illness.

The purpose of the Historical Chronology is to inform a Mental Health Professional of episodes of illness so that treatment may be obtained for an ill person. This document can be maintained by adding or deleting information in a timely manner.

The creation of the **Historical Chronology** must be approached with respect for the individual who is ill. Only information that points to the legal definition required for obtaining treatment needs to be included. We as family members are creating this document so that our ill relative may receive the treatment that they need to begin their own recovery.

The **Client Profile** may accompany or be an alternative to the historical chronology. Page one is designed as the identification section. Knowing this important information gives a professional key contacts for the client. Page two contains a current history of the client's diagnosis, last exam, allergies, and medications. Page three gives a brief summary of the ill person's education, skills, and accomplishments.

Together the **Historical Chronology** and the **Client Profile** present a professional picture of the person accessing a treatment facility. The family's information presented in this manner should be accepted and respected by the staff of the treatment facility.

Composing a Historical Chronology

DIRECTIONS:

The following questions are only meant to stimulate your thought process regarding your ill relative. If you wish to disregard these questions and compose your own chronology of the events surrounding the onset and progression of mental illness, please do so. Use only specific concrete language including dates and locations. Our best method of communication with professionals is to be precise and adhere to only factual information.

1. Describe the circumstances in which you first realized that something was wrong with your relative.
2. Please describe your perspective prior to the illness, your relative's role in the family referring to role as brother, son etc.
3. After the onset of the mental illness, what specific changes occurred in your relative's relationships within the family or with his/her social circle?
4. Has your relative ever acted in a threatening or violent way that you are aware of? Please describe.
5. How do you feel that you have been affected by your relative?
6. Describe any emotional or physical adverse affects that your relative has suffered as a result of mental illness.
7. Since your relative has been in treatment, what changes have you observed?
8. Please list the dates, location, and professionals who have been involved with your family on a treatment basis.
9. Please describe your personal relationship with your relative before and after the onset of mental illness.
10. Is there anything else that you would like to add?

Historical Chronology: Interviewer Notes

When the professional includes, listens to, acknowledges and refers family members, family members become a resource and support to both the client and the professional.

The following questions will elicit memories of the events that the family identifies as leading to the onset of the illness. In our experience as a family compiling this information, each member's views told an important part of the story. It is essential to include all family members in the information gathering process. They can respond in writing by letter or email or verbally in an interview. Confidentiality Laws do not prohibit families from offering information. It is normal, in my experience, for the story tellers to be emotional in the re-telling of these events. Family members may not have shared this information with anyone. Families need to be acknowledged for their own courage under these circumstances and referred to community support. Information regarding NAMI support groups or the Family to Family Education Program can be obtained at www.nami.org.

1. Prior to the onset of the disease, try to identify examples of "episode warnings" that your relative was having trouble.
2. Describe each example:

   A. How did each episode affect the individual?

   B. Did the episode affect you? If so, how?

   C. Were any family members (or anyone else) affected?

The experience of having a mental health professional say "Tell me about the mental illness" allows the family to articulate what they know about the disease and to feel validated about their own experiences. In our situation, we were interviewed briefly by a family psychologist. The psychologist asked for a description of the current problem (or set of problems) facing us and then simply asked if anyone of us in the group felt that we had been

affected adversely by our relative,s illness. The process identified individual(s) in the family who needed additional support and also broke the silence about the illness in the family. Appropriate referrals were offered. The psychologist acknowledged us as a family for coming forward to seek proper care and treatment for our relative. He answered a few questions and ended with a reading reference, "Surviving Schizophrenia, a Family Manual" by E. Fuller Torrey M.D. I followed up with a letter asking family members to give me information about their experiences regarding the illness (see "Letter of Appeal for History" in manual). This compilation of information by the family became the "Historical Chronology".

When the family shares their experiences, many good things occur:

1. Reliable information is exchanged about the brain disorder.
2. The family feels acknowledged and validated regarding their own experiences.
3. The family gains knowledge about the brain disorder
4. The client receives support for their illness.
5. The mental health professional learns what has and what has not worked.
6. The family and ill member are empowered to support each other.

CONFIDENTIAL

Do you give permission to the professional to share this information with the ill person?

Yes ____ No ____ Signed _____ Dated _____

Historical Chronology for: _____

Presenter: _____

Relationship: _____

Episode # _____ Date: _____ Location _____

Description:_____

_____

_____

How did this episode affect this person?

_____

_____

_____

Did this episode affect you? If so, how?

_____

_____

_____

Was anyone else affected by the episode? Please explain.

_____

_____

_____

_____

_____

Outline for Historical Chronology

I. Purpose of History

- Introduction
- Access Treatment.
- Update medication history.
- Summarize individual's treatment history.

II. Length of Document

- Two pages or less

III. Content of Document

- Use concrete terms. Never use personal philosophy.
- Describe information precisely, use dates and locations.
- Make history as objective as possible.
- Incorporate goals of your relative.
- Incorporate other relative's or friend's contributions.
- Document should exhibit entire family's experience.

IV. Presentation

- Document should be typed neatly so it is easily read, copied, or faxed.
- Submit document with a cover letter of introduction.

Compilation of Historical Chronology Received from Family Members

This listing of events represent examples of behavior that have concerned us all during recent years. This is only a sampling of incidents to give you an idea of his behavior prior to his incarceration in 1989.

Summer to early Fall 1985 Roger leaves Montana where he had been in residence since 1979. He drives his pickup truck alone to California and telephones his aunt and sister. He has been living out of his truck and working at transient jobs until he decides to contact family. He stays with aunt one night, aunt is afraid of his "wild eyed desperate look" and asks sister to take him home. Sister and husband house him for 4–6 weeks while he works construction. He slowly becomes more paranoid about people not liking him and finds it difficult to go to work. He moves into an apartment, which sister and aunt arrange, and he calls his wife to come with their things from Montana. Wife arrives, relationship stormy.

Within only one week, his construction tools are apparently stolen from his truck, he refuses aunt's offer to replace them, he quits job, he tells wife to leave, and he threatens to go to Mexico to find a new life. Sister calls father, father flies from home and stays with him for about three weeks (remainder of rental time), asking him to go to the doctor, Roger refuses and leaves for Texas and Florida, returning to Montana where he continues to live until early 1987 when marriage has final break-up.

October 1986 Roger is at home for a family visit where he is helping to move a sister's belongings into storage. He becomes annoyed with brother-in-law and punches him in the face.

Compilation of Historical Chronology Received from Family Members (Con't.)

February 1987 Roger telephones Father, who is wintering in California with his sister, and asks him if he can stay in his home. Father consents, Roger begins residence with father who supports him financially until his incarceration in 1989.

Spring 1987 Roger is asked by sister to help a friend pack belongings in storage, Roger refuses at the time but appears at storage unit where sister's friend has arrived alone. As friend relates story Roger started acting strangely almost immediately. Being verbally abusive and antagonistic, using foul language and threatening violence against the friend. Friend was naturally quite afraid and thought him to be mentally unstable. As the moving progressed, Roger spit on friend's feet continually and, when moving heavy pieces of furniture, Roger would push friend against the wall, pinning him with the furniture.

Friend says that he was frightened at the time but was afraid to antagonize further by saying anything. He just wanted to get the job done and get out of there. Finally after continued pushing and shoving and verbal threats, Roger locked sister's friend in the moving van and refused to let him out. Friend finally convinced to unlock the van and then went immediately to manager and had Roger removed from the premises.

Unfortunately, this friend did not tell the family of this experience with Roger until one year later.

Winter 1987 Roger resides alone while his father winters in California.

His three children, ages 14, 18, and 21, go to visit him. During the visit, he appears anxious and confused, threatens to go to "beat the shit out of a punk". Later, as his oldest daughter recalls, "Dad started telling me that someone was trying to kill him and had been for a long time. He said that they had tried to gas him at the house.

Compilation of Historical Chronology Received from Family Members (Con't.)

He used celebrity names, i.e. Hugh and Christine Heffner, and appeared to be very anxious and afraid." (Later, in April Roger burned the neighbor's house down, saying that they had tried to gas him.)

Christmas 1987 Roger's son relates that he becomes very fearful of Roger when he goes out in the woods alone with him to chop down a Christmas tree. In son's words, "Dad started talking about celebrities who wanted to kill him. I was very scared. I just didn't know what my Dad was going to do."

Summer 1988 Roger is arrested for resisting arrest and assault while driving through a road construction area on the Highway. Please refer to County Police report In file.

July 1988 Roger sells his pick-up truck and buys a bus ticket to California. Roger arrives in town and calls aunt. Aunt wary of being alone with him and asks sister's husband to pick him up. Roger stays for one week at sister's house and family returns him by air to home state for court appearance regarding arrest.

Spring 1989 Roger writes for and receives his FBI and CIA records. He continues to appear very paranoid and confused. He complains of odors bothering him constantly and tasting odd things. At times he speaks incoherently. Brother calls sister and father, asking them to come to father's house to investigate house fire next door. Brother suspicious after checking in at father's house after fire and finding Roger gone and house left in a bizarre state. (Pictures available in file) All appliance unplugged, covers on all electrical outlets, blankets covering open windows, all sinks filled with water, light bulb bases covered with paper and screwed back in lamp sockets. Presently Roger continues to believe that the neighbors were trying to "gas" him and that he set the fire to "defend himself."

Compilation of Historical Chronology Received from Family Members (Con't.)

April-May 1989 Roger claims he was not involved in fire next door. Family believed him, and sister takes him for Vocational Rehabilitation appointment. He is unable to fill out questionnaire or participate in group interview. He talks incoherently on the way home. Family sits down with Roger and gives him alternatives, he can either go for treatment or he is on his own. Roger asks for money and then leaves with just a knapsack on his back.

Within a couple days, aunt receives phone call asking for money, which she sends him. Next, father receives incoherent phone call from Roger in bus station. Within a few days, we hear that he has arrived at uncle's house. Meanwhile, a longtime neighbor friend comes forward as an eye witness to the arson. We arrange with State Police Department to pick Roger up and he is extradited to home state and admitted to state prison in July 1989.

How to Complete a Client Profile

Complete as much of the information as possible.

Page One: Client Profile

Photo: *Paste or tape a recent photo of the person.*

Name: *Complete Name* D.O.B.: *Complete date of birth*

SSN: *Write Social Security number, if available*

Medicaid: *Write Medicare or Medicaid number*

Case #: *Write agency name and case number*

Key Family Members: *Write complete names, addresses, and phone numbers of parents, siblings or any other important* ***Key Contact*** *such as spouse or friend.*

Current Residence, Last Residence: *Write complete addresses of the persons current and previous residence.*

Current Care providers — Physician, Mental Health Provider, Psychiatrist, Dentist, Opthamologist, other: *Complete names, addresses and phone numbers for as many of these professionals as possible.*

Page Two: Client Profile

Name: *Complete Name* D.O.B.: *Complete date of birth*

Fill in gender of person.

Provide ethnic background information.

Complete languages person speaks.

Provide physical description.

Provide diagnosis, date of last exam.

Provide information regarding any special problems (treated or untreated).

Provide information that is important for a professional to know.

Provide information on any allergies and types of reactions.

Page Three: Client Profile

Name: *(Complete Name)*_____

D.O.B.*: (Complete date of birth)*

Historical Chronology: Compose a history of the events regarding the onset and progression of the person's mental illness. Use only factual, specific, concrete language including dates and locations in your writing.

Accomplishments, Skills, or Talents: Describe the person's accomplishments,(i.e.,) life experiences they are proud of. List skills and talents they have shown throughout their life.

Education: List schools or any workshops they have attended.

Special Problems: Use this space of describe any unique problems and successful treatments this person may have experienced.

Comments: Any other information you or the client may wish to include.

Client Profile: Interviewer Notes

Identification + Healthcare + Accomplishments = Comprehensive Profile

When the client and their family submit information about the client's identification, healthcare, and skills and accomplishments, the professional obtains a comprehensive history, referred to as the Client Profile.

The Client Profile questionnaire is a three-page format designed to create an easy flow of clear, concrete information between the client and their family, and the mental health professional. The client and their family may be interviewed together or individually.

Page One / Identification Information

- Identification Information including Photo

  A photograph from the family gives a good historical picture of the client.

- Key Family Members, Parents and Siblings, Key Contact

  Addresses, emails, and phone numbers of parents, siblings are listed. Key contact person for information or in case of emergency.

- Current Care Providers

  Physician, Psychiatrist, Opthamologist, Mental Health Professional, Dentist, and any other health care provider's contact information is important and can be provided by family members.

Page Two / Healthcare

The second page of the Client Profile describes identification, diagnosis, and health history. A medical alert describes important information about existing or past conditions. The behavioral alert describes existing or past problems, i.e. anger management, substance abuse. Allergies, medication information, and other

regimes are all important healthcare information. History of hospitalizations and incarcerations can also be provided by family.

Page Three / Accomplishments

The third page of the Client Profile is designed to elicit social and education information about the client from the family. Specific problems and treatment, successful and/or unsuccessful, can also be discussed. Families often know what has and hasn't worked.

Post Script to Professionals from a Family Psychiatrist

Psychiatrist Thomas Henley, director of a community mental health clinic in southern California, states, "Unfortunately, the popular method of therapy suggests that including the family and patient jointly in the clinical setting is somehow 'out of the norm'. However, if the professional begins with open communication and structures (joint interviews) as routine, the therapist can take care of any future problems, by indicating in their remarks to the patient at the outset, that the family members are invited to participate . . . the professional needs to structure the assessment and interview so it favors inclusion of the family. An important benefit is . . . the family member as a witness to important communications regarding medication, crisis services, etc. . . . We as professionals cannot let the overly strict interpretation of confidentiality prevent us from providing good initial assessment to the patient and their family."

Advocate's Tool Box

Interpersonal Tools

- Communication
- Negotiation
- Networking

Organizational Tools

- Assessment & Planning
- Knowledge & Understanding of Patient
- Written Communication
- Presentation Skills
- Working Knowledge of your local Mental Health System

Intrapersonal Tools

- Awareness
- Empathy
- Respect

These Advocacy tools are skills we use everyday. In the workshop we discuss using them to accomplish good diagnosis and treatment, but think bigger than that. Skills like these come in handy in all kinds of situations.

Client Profile

Photo

Identification Information:

Name: _____

D.O.B.: _____

SS#: _____

Medicaid#: _____

Case#: _____

Current Residence: _____

_____

Last Residence: _____

_____

Key Family Members:

Parents _____ Siblings _____

_____ _____

_____ _____

Key Contact: _____

Current Care Providers:

Physician: _____ Mental Health: _____

_____ _____

Psychiatrist: _____ Dentist: _____

_____ _____

Opthamologist: _____ Other Health Care: _____

_____ _____

Client Profile

Name: _____ D.O.B.: _____

Sex: _____ Ethnicity: _____ Language:_____

Height: _____ Weight: _____ Eyes: _____ Hair: _____

Diagnosis: _____

Date of Last Exam: _____

Medical Alert: _____

Behavioral Alert: _____

Allergies: _____

Medication:	Dosage:	Date Began:
1. _____	1. _____	1. _____
2. _____	2. _____	2. _____
3. _____	3. _____	3. _____

Other Regimes (i.e.) special diet, vitamin therapy:

1. _____

2. _____

3. _____

Hospitalizations:	Dates:	Locations:
1. _____	1. _____	1. _____
2. _____	2. _____	2. _____

Incarcerations:	Dates:	Locations:
1. _____	1. _____	1. _____
2. _____	2. _____	2. _____

_

Client Profile

Name: _____ D.O.B.: _____

Historical Chronology: (submitted by client and family)

Summarize history or attach complete history

_____

_____

_____

Accomplishments: _____

_____

Skills or Talents: _____

_____

Education: _____

_____

Specific Problems:

1. _____
2. _____
3. _____

Treatment:

1. _____
2. _____
3. _____

Comments:

_____

_____

Chapter 9
Letters

Letters can be our most effective tool in the act of advocacy. We can use them to introduce ourselves and our family. We can make specific requests or complaints. We can write special letters of acknowledgment. Most of us are out of practice when it comes to sitting down to write more than a holiday greeting. However, we have all had the experience of writing sometime in our lives.

The following pages list important points, the make-up and the elements of good letters. I have included samples of letters that were successful in the advocacy work that I have done. Please feel free to use them.

When you advocate by writing, it is imperative to have a clear grasp of what you want to say. Find a friend and review your thoughts out loud. Think about the tone you wish to use and start jotting down thoughts. When you are clear, succinct, and polite, the reader is more likely to understand what you are saying.

When you sit down to write your next letter, read over the "Elements" of the type of letter you are writing. Samples of actual letters are included in this section for your use too. Approach your advocacy logically and thoughtfully as you would any other business in your life.

The following pages list important points: the "make-up," and the "elements of good letters." I have included samples of letters that succeeded for me in my advocacy work. Please feel free to use them.

Important Points in Letter Writing

- Have a clear grasp of what it is you want to say.
- Review it out loud with a friend if possible.
- Determine the tone you wish to use.
- Capture the tone by jotting down particularly appropriate phrases from your conversations about the issues.

Letter Elements

1. Attention line
2. Reference line
3. Subject line
4. Salutation
5. Body of letter
6. Complimentary close
7. Signature
8. Address, phone number, fax number
9. Enclosure
10. CC

The Makeup of a Good Letter

Create the opening

The writer should make every effort to word his or her thoughts clearly. This statement is especially important in the opening paragraph of the letter. The first paragraph sets the tone for the letter. It should capture the reader's attention.

State the purpose of your letter or reason for concern

A. Use tactful easy to understand language. Simple words, clear-cut and direct, are easy to read and understand. Try to use natural, everyday expressions.

B. Organize your language carefully and concisely. Give accurate precise information. Establish your personal credibility if necessary.

C. State your personal commitment to be of assistance.

Devise a friendly way to close

Thank the person by leaving the clear impression that you wish to work together.

Review

Look forward to revising your letter. Do not be afraid to change or rearrange for the final letter.

Elements of an Introduction Letter

Introduction: Make your introduction immediately.

Body: Present relevant professional information.

Give your evaluation and recommendations.

Close: Close by offering more information upon request.

Elements of a Request for Appointment Letter

Introduction: Open by reminding your addressee that you have met or talked before.

Body: State your desire to meet or talk, and suggest a date or time.

State that you will call later to confirm the appointment.

(This allows the opportunity to speak together prior to the appointment to better assess the situation)

Close: Close in a friendly manner.

Elements of a Complaint Letter

Introduction: Get directly to the point (without being rude). Use the opening to tell "what" and "why." Save the details for the body of the letter.

Body: Explain the sequence of events in an orderly way.

Close: Do make clear that you consider performance below par and express hope for improvement in the future. Do not belabor your disappointment.

Elements of a Thank you letter

Introduction: Thank the person and specifically state what they did for you.

Body: Describe the benefit you derived.

Close: Express appreciation and offer a compliment.

Request to Director of County Mental Health Services Involuntary Treatment

Thomas Jones
Supervisor
Involuntary Treatment, Podunk County
Anytown, Anystate

Dear Mr. Jones,

The purpose of this letter is to introduce our family and express our serious concerns regarding the release of our relative, Roger Smith, from the State Prison on August 11th, 1990. We all care for Roger very much, however we know that he is seriously ill and he requires hospitalization.

At this time no member of our family is willing or able to care for or financially support Roger. We feel that his emotional problems and threatening behavior constitute a danger to which we cannot expose ourselves or our loved ones.

The serious nature of the crime committed in April, 1989, and his repeated statements to family members as recently as June 1990, that, "I had to do it to defend myself," show a serious disturbance in Roger's reasoning ability. In our belief this establishes him as a grave danger to society because he shows no remorse, and in fact could repeat this crime believing it to be a reasonable course of action against a perceived threat.

In the past, Roger has always turned to family members for both emotional and financial support whenever he has been faced with a troubling situation in his life. Of course, we have all tried to do our best to support him, but at this point, upon his release from the State Prison, Roger appears to be unable to take care of himself and is beyond our control.

Based on recent visits by family members to the state prison he is only able to present himself semi-rationally for short periods although sometimes for as long as two hours prior to exhibiting bizarre behavior. When we asked Roger what he was experiencing, he told us that, "I hear voices all the time, and I don't like what they are saying to me, I smell things all the time, and I can taste things like the dust on the floor." However, when asked to take responsibility for treatment he refused, (a reply which is typical of his totally uncooperative behavior) even with day to day activities. Enclosed is a listing of Roger's behaviors that have concerned us during recent years.

At this time we have felt it necessary to notify Ms. Goodwill, mayor of Small town, and the Police Department, in addition to local and state officials. We feel that all persons involved in this matter bear the responsibility for Roger's future behavior.

Since Roger has been incarcerate, we have all observed that he has become more seriously ill. He has not been willing or able to participate in treatment or placement planning, and accordingly will probably end up on the street if he is not hospitalized for supervised treatment. This lack of care would obviously be both a disservice to Roger as well as to the community in which he is forced to wander until another episode of his illness leads to a more serious offense.

As family members of Roger, and as responsible citizens of our communities, we want to prevent yet another person's property damage or injury. Please consider carefully all the information concerning Roger. Only you can provide the opportunity for him to get the treatment he so desperately needs and deserves.

Thank you for your kind attention to this very serious matter.

Sincerely,

Signature

Enclosure: 1

cc: Ms.Goodwill, Mayor of Small town
Mr. Smith, Father
Mr. Smith,Brother
Ms. Smith, Daughter
Mr. Smith, Son
Mrs. Jones, Sister
Ms. Smith, Sister
Mrs. Concerned, Aunt
Mrs. Anxious, Aunt

*This letter and attached listing was composed by Mrs. Advocate, sister. However it is a composite of information received from the entire family.

Request to Local Legislator for Evaluation for Involuntary Treatment

Senator John Smith
State Capital Campus
The State Building
Room 425
Anytown, Anystate

Dear Senator,

The purpose of this letter is to ask for your help with a very serious problem our family faces. Our relative, Roger is being released from the State Prison in Anytown on August 11th.

The problem is that Roger has served his completed term which allows him to walk out free with no supervision. He has refused to be treated for his mental illness. He has also refused to participate in any placement planning, and continues to say that he committed his crime of arson to "defend myself". Naturally we are very concerned that without treatment Roger poses a serious danger to the community.

Sadly we are forced to seek an involuntary commitment authorization for Roger because of his lack of cooperation and his critical need for supervised treatment. The State Prison staff are in complete agreement with us. They are not optimistic that the Involuntary Treatment Staff from Podunk County will judge him eligible for admittance to the State Hospital.

Therefore, since Roger is one of your constituents, we are asking for your intervention to advocate strongly for Roger's treatment, and avoid the threat of another serious crime being committed causing property damage or personal injury.

We have enclosed a letter that has been sent to Mr. Bureaucrat, Supervisor of Involuntary Treatment for Podunk County, which expresses our family's concerns. If you should require any further information regarding Roger's condition, his Counselor is Ms. Hardworker, State Prison, telephone 911-8011. Her office hours are 7:00 a.m. to 3:00 p.m., Sunday through Thursday.

Thank you very much for your serious attention to this very pressing problem.

Sincerely,

Signature

cc. Ms. Hardworker
Mr. Jones

History & Request for Extensionof Involuntary Treatment

Mr. John Adams
Prosecuting Attorney's Office
State Hospital

Dear Mr. Adams,

The purpose of this letter is to introduce myself and to express my serious concern regarding my brother Roger, who was admitted to the State Hospital on Saturday, August 11th. As I am sure you know, Roger was transferred from the Special Offender Center in Anytown for the purpose of receiving a complete mental health evaluation, as directed by the County Involuntary Treatment Staff.

My serious concern is that, on August 11th, Roger had served his maximum sentence and would have been allowed to walk out free, with no supervision. During his period of incarceration, he has refused to be treated for his mental illness, refused to participate in any placement planning with his family or the staff, and has continued to say that he committed his crime of arson to "Defend myself". Naturally, we are very concerned that without treatment, Roger poses a serious danger to the community and in particular, to his family.

At this time, no member of our family is willing or able to care for, or financially support Roger. We feel that his emotional problems and his threatening behavior constitute a danger to which we cannot expose ourselves or our loved ones.

Although Roger has not given permission for the release of his records so that our family may be informed of his condition, I have visited him on five separate occasions during the last year. I include the following information to illustrate what seems to be clear evidence that my brother's reasoning ability is truly impaired

and that he requires hospitalization and supervised treatment at this time.

On my last visit with him (about seven weeks ago), his counselor sat down with us for about ten minutes. She asked Roger if she could tell me about an episode that had occurred the previous morning. Roger consented and she asked him to tell me the story. He agreed and turned to me and said "They came to get me, the satellite came again!" His voice was filled with anxiety. "They were trying to take me away! I had to do something to defend myself." The counselor asked, "And what did you do Roger?" He responded anxiously, but trying to appear nonchalant, "I just spilled some of my coffee." She corrected him saying, "No Roger, you threw your breakfast of prunes against the wall, didn't you?" To which he nodded yes.

His counselor then added, "And this isn't the only episode, is it? It's happened before hasn't it, Roger?" Again he responded by nodding.

I followed his story by asking Roger if he was aware that he had a brain disorder called Schizophrenia. He responded by saying, "I knew it had to be something serious since they put me here." We talked about the fact that three of his first cousins had been diagnosed with Schizophrenia. (Two of the young men are receiving treatment at State Hospital. The third boy committed suicide.) He said he knew. His comment was "That didn't mean that they were stupid, did it?"

I agreed and restated that certainly mental illness does not mean that a person is stupid. However, it does mean that a person needs treatment as in other diseases. He seemed to accept the idea that he was ill and asked questions like, "How long do you think that I have been sick? When I asked him one more time to please consider treatment and medication, he refused adamantly and insisted that it would be better to "Just wait and see." Even when I suggested that

his refusal may mean hospitalization later on he only responded by saying, "I'll just have to do what I have to do."

Later, during my last visit with him, I asked him what he was experiencing. He told me, "I hear voices all the time and I don't like what they are saying to me. I smell things all the time and I can taste things like the dust on the floor." I commented that all this stimuli must make him tired. He answered, "You just can't understand what I have to put up with. Nobody understands."

Unfortunately since Roger continues to refuse treatment, we as his family and only support group are compelled to seek involuntary treatment status for him. I understand that his hearing tomorrow, August 15th might enable him to be detained at the hospital for an additional 14 days. If I can be of any assistance in this process, I would be happy to do so.

Enclosed for your information is a listing of events which represent examples of Roger's typical behavior since 1985.

Thank you very much for your kind attention and serious efforts on behalf of treatment for my brother, Roger. If I can be of any assistance, please call me.

Sincerely,

Signature

Home telephone:

Office telephone:

Fax:

Thank You and Request for Information

Ms. Sally Social Worker
Supervisor
Admitting Psychiatric Unit
State Hospital
Anytown, Anystate

Dear Ms. Social Worker,

Please accept my thanks once again for your attention and understanding regarding my brother Roger Smith, recently admitted to Ward E-1 under your supervision. As you may recall, I telephoned you August 10th about Roger's impending admission.

Since that time, he has been authorized to receive involuntary treatment until his next hearing date scheduled for August 29th. Although I have not spoken with any member of his Treatment Team, I imagine that he is undergoing a period of evaluation at this time.

My own background in Social Work, and my serious interest in the field of Mental Illness (due to my brother's disease) has led me to read Dr. E. Fuller Torrey's book "Surviving Schizophrenia A Family Manual". The attached pages titled, "The Ideal Diagnostic Workup" are my only frame of reference for the evaluation Roger is currently receiving. May I request that one of the Treatment Team Staff telephone to inform me of Roger's current condition, and also describe the procedures that he is now undergoing?

Again, I certainly appreciate your time and kind attention in this matter. I look forward to hearing from you or one of your staff members soon.

Sincerely,

Signature

Home telephone:

Office telephone:

Letter of Complaint

Ms. Overburdened
Social Work Department
State Hospital
Ward X
Anytown, Anystate

Dear Ms. Overburdened,

Allow me to begin this letter by saying how much our family enjoyed our visits with Roger over the Thanksgiving holiday.

Although we know that he has a long way to progress, we were all thankful to see that Roger is much improved since he has been taking medication regularly.

We were all disappointed however, that our scheduled family meeting with the Treatment Team on November 21st did not occur. Although our family members joined Roger in the conference room to begin the meeting, you were the only professional who met us. We understood your statement at the time since Dr. Noshow and the rest of the team were not present you could not discuss Roger's case, and in addition, you advised us that you would need a written Release of Information signed by Roger even though he was present and had given his verbal consent. Three of us traveled 1200 miles for this important meeting regarding our brother's care and treatment. Naturally we were very disappointed at the apparent lack of cooperation. You were unable to give us a reason that afternoon as to why the other staff were unable to join us. We sincerely hope that the complete Treatment Team will be present for our next meeting.

Enclosed is a copy of my letter of November 7th in which I asked for a written statement from you regarding the hospital's legal obligation concerning Roger's discharge. As I stated in the letter, "In other words, what do we have the right to expect from you (the

hospital) regarding placement plans and responsibility for legal supervision which will protect Roger from his illness, and at the same time safeguard the community from Roger's behavior?"

On November 15th, Dr. Cautious, a member of your staff, called to inform me that my letter had been sent to the State Attorney General's office for an answer. Up to this time I have not received a response from the State Hospital or the Attorney General's office. Could you advise us as to when we might expect a reply, or let us know immediately who we may contact at the Attorney General's office for an answer?

Some good news my father discussed with you is that during our Thanksgiving holiday Roger did sign an "Informed Consent for Disclosure of Records and Information" (X23-07)(copy enclosed) as you requested during our November 21st meeting. On that form, which was submitted to Ward X staff six weeks ago, we requested copies of his Psychiatric Assessment and Social History. My father has not received copies of either report. According to my father, in his recent discussion with you regarding this information, you told him that although Roger had signed a written release for this information, you still required his additional verbal agreement.

Surely, by your own statement at our November 21st meeting, Roger had previously verbally agreed to the release of information on more than one occasion, and he repeated his agreement during the meeting. Ms. Overburdened, would you please clarify what exactly is required for our family to receive information from Roger's file regarding his care and treatment. Please send the reports immediately to my father.

We are very concerned about Roger. Specifically we understand that January 22nd is the final date of his 90 day authorization for involuntary treatment. Although his condition has improved, Roger still exhibits disordered thinking regarding his responsibility for the act of arson in April of 1989. We agree with you that he requires some additional hospitalized care and treatment.

We want Roger to receive the best treatment available for his disease. He has been receiving Triliphon for approximately four months. However, he appears to exhibit delusional thinking. In the last conversation Dr. Goodguy had with my father, (prior to the doctor's leaving State Hospital last month) he suggested that Clozaril may be a positive alternative medication for Roger.

Our first cousin has been hospitalized for about eight years, in another state, with a diagnosis of Schizophrenia. He has recently been prescribed Clozaril on an experimental basis. Does a similar opportunity exist at this state hospital? Is your institution involved in procuring permission to use or test this drug which we hear has been so successful? I have enclosed a recent article, "Cost Cut on Drug for Schizophrenia," for your review.

Ms. Overburdened, since my father and I are both former Social Work professionals, and I am currently serving as President of the local Alliance for the Mentally Ill (AMI), we try to be well informed. When my brother became ill, I promised myself that I would try to do for him what I would hope that my family would do for me, if I became ill. Our purpose is to pursue the best possible care and treatment for Roger. I sincerely hope that you and the Treatment Team consider our family helpful advocates during Roger's hospitalization.

Thank you for your continued efforts toward Roger's treatment and recovery.

Sincerely,

Signature

Home telephone - Office telephone - Fax _____

Enclosures, three

cc. Dr. Noshow, Psychiatrist
Ms. Very Cautious, Ph.D.
Mr. In Charge, Ph.D., Acting Superintendent

CHAPTER 10

Communicating with Each Other

When a child or sibling has a serious brain disorder, episodes of illness AND periods of clarity manifest. These periods of clarity which I refer to as "Windows of Opportunity," offer us a chance to communicate with our relative during illness. These "Windows" are recognized by every family member I have talked to.

Communication work when done inclusively with all of those players who will be affected may take a little longer to create, but generally works out better for everyone in the long run. When I asked my brother, "What's the difference between you and all those other people on the ward who are still there?" He answered, "We (the family) could all sit down at the table and talk, and nobody would get mad and leave." This "sitting down at the table" and "nobody leaving" is one example of the family working together as a team.

When our child or sibling has a serious brain disorder, they experience episodes of illness AND periods of clarity. These periods of clarity which I refer to as "Windows of Opportunity" offer us a chance to communicate with our relative during illness. These "Windows" are recognized by every family member I have talked to. We can all remember times when our relative is feeling calm and we can discuss a problem clearly and succinctly. It is never going to be perfect. Talking with any ill person requires compassion and respect. We need to communicate clearly so that the person hears us. We need to listen thoughtfully so we can hear what they are saying.

It is helpful to bring only one subject up at a time. About a month after my brother was released from the hospital, I traveled to visit him and to arrange housing for him. Naturally I had concerns about his ability to maintain his own fragile stability in new housing. I chose a time after dinner when we were both happy and relaxed. I remember we were sitting beside each other on a couch while another sister washed dishes in the kitchen. The warm feeling resembled many Sunday evenings in our parents' living room. I decided that the time was right. We had a short and good talk about two important issues. It probably lasted about three or four minutes. My brother agreed to take his medication and he also agreed to call me if he had a problem that he needed help solving.

In my own experience four things made our conversation successful:

1. Become familiar with what a "window of opportunity" looks like.
2. Know what you want to say and say it clearly.
3. Do not philosophize: communicate in a concrete manner.
4. Make it brief.

To be able to communicate again with my brother is a gift. I cherish and respect it. During bouts of illness, do not attempt too much. Just like anyone of us when we are very ill, relatives of ours feel better and safer when life around them is simple and not too much is asked of them. Remember during ill periods they may find it extremely difficult to get up in the morning.

Characteristics of Helpful Families

1. The person is ill, accept that.
2. Attribute symptoms to the illness.
3. Set realistic and attainable goals.
4. Include the ill person in the family.
5. Keep a loving distance.
6. Create a calm atmosphere.
7. Give frequent praise.
8. A specific criticism or correction should be stated calmly and in a positive manner.

Designing and Setting Limits with the Ill Person

It is best to establish limits when you and your relative are calm and clear thinking.

Unless a major transition is occurring (e.g., relative is returning from the hospital) it is a good idea to set one limit at a time.

1. Consider exactly what behavior you want to change.

Be realistic about the amount of energy it will take. Make sure you are prepared to follow through.

2. Plan the consequence.

Use one that is appropriate to the seriousness of the behavior and one you are willing to carry out, (e.g., You would not want to tell your relative that you will never talk to them again if they curse in your house).

Some common consequences are: docking privileges (spending money, TV watching time). Reward the desired changes in behavior (dinner out at the restaurant of choice, participating in special outing, etc.).

3. Inform your relative.

Be simple and clear in communicating the limit and consequence.

Do not get defensive or give long explanations.

Give your relative a chance to ask questions and give input.

Negotiate if it seems reasonable.

Writing down agreements or contracts often helps keep things clear.

4. Implement the consequence.

This too is best done when you remain calm and clear. It is essential to follow through exactly as you said you would.

It is important to acknowledge and praise any part of the limit that was adhered to.

5. Modify or revise the limit, consequence, or contract, as experience indicates would be productive. This should be done in a clear and explicit way.

Visits are extremely important. They give people a sense of order and predictability in their environment. This is especially reassuring for people whose external world is fraught with chaos and disorganization.

Chapter 11

Crisis Information

Please do not wait for a critical situation to happen prior to having a plan. Arrange a procedure with your family so that you know who to call for help or support. You and your ill relative will have an easier time.

The Crisis

A serious crisis will occur sooner or later with a family member afflicted with schizophrenia or a major affective disorder. When this occurs there are some actions which you can take to help diminish or avoid the potential for disaster. Ideally you need to reverse any escalation of the psychotic symptoms and provide immediate protection and support to the individual with mental illness.

Seldom if ever will a person suddenly lose total control of his or her thoughts, feelings, and behavior. Family members or close friends will generally become aware of a variety of behaviors which give rise to mounting concern such as: sleeplessness, ritualistic preoccupation with certain activities, suspiciousness, unpredictable outbursts, and so on.

During these early stages a full-blown crisis can sometimes be averted. If the person has been evaluated and prescribed medication, he or she may have ceased taking them. If you suspect this, try to encourage a visit to the physician. The more psychotic the patient, the less likely you are to succeed.

You must learn to trust your intuitive feelings. If you feel frightened or panic-stricken, the situation calls for immediate action. Remember your primary task is to help the patient regain control. Do nothing to further agitate the scene.

It may help you to know that the patient is probably terrified by the experience of loss of control over thoughts and feelings. Furthermore, the "voices" may be giving life-threatening commands. Messages may be coming from the light fixtures; the room may be filled with poisonous fumes; snakes may be crawling on the window.

Accept the fact that the patient is in an "altered reality state." In such situations the patient may "act out" the hallucination, (e.g.)

shatter the window to destroy the snakes. It is imperative that you remain calm. If you are alone, contact someone to remain with you until professional help arrives. In the meantime, the following guidelines will prove helpful:

Do not threaten. This may be interpreted as a power play and increase fear or prompt assaultive behavior by the patient.

Do not shout. If the mentally ill person seems not to be listening it isn't because he or she is hard of hearing. Other 'voices' are probably interfering or predominating.

Do not criticize. It will only make matters worse. It cannot possibly make things better.

Do not squabble with other family members over "best strategies" or allocations of blame. This is no time to prove a point.

Do not bait the patient into acting out wild threats; the consequences could be tragic.

Do not stand over the patient if he or she is seated. Instead, seat yourself.

Avoid direct continuous eye contact. Avoid touching the patient. Comply with requests that are neither endangering nor beyond reason. This provides the patient with an opportunity to feel somewhat "in control."

Do not block the doorway. However, do keep yourself between the patient and the exit.

In the final analysis, the patient may have to be hospitalized. Try to convince him or her to go voluntarily. Avoid patronizing or authoritative statements. Explain that the hospital will provide relief from the symptoms and that the patient will not be kept if treatment can be continued at home or outside the hospital in some other protected environment. Do not be tempted to make ultimatums such as, "Either go to the hospital or leave the house." This invariably intensifies the crisis.

During these crisis situations try to arrange to have at least two people present. If necessary one person should call the County-Designated Mental Health Professional, the other person remain with the one in crisis. In King County, WA the Crisis Clinic handles after-hours or weekend phone assessments. All other counties have 24-hour direct lines. Because the Crisis Clinic lines are frequently busy, it is recommended that you make a preliminary phone call directly during regular business hours. Inform CDMHPs that you may be requiring their assistance during the next day or two.

If indicated, call the police. Instruct them NOT TO BRANDISH ANY WEAPON. Explain that your relative or friend is in need of psychiatric assessment and that you have called them for help. Tell the officer that the patient has or has not been hospitalized previously and that he or she does or does not have access to any weapons. In short, try to prepare the officers for what to expect. Remember –

THINGS ALWAYS GO BETTER IF YOU SPEAK SOFTLY AND IN SIMPLE SENTENCES.

1998 NAMI Conference Handout

Mental Health and Crisis Services

Please list your local community phone numbers here for easy reference.

Crisis Clinic

CDMHP – County Designated Mental Health

Professional

Local Hospital

Local Mental Health Agency

Local Mental Health Caseworker Services

Local Police, Fire, Ambulance **911**

Mental Health OMBUDS

NAMI (Local Affiliate)

NAMI (State Offices)

NAMI (National Helpline) **1-800-950-6264**

CHAPTER 12
Community Advocacy

Jane Fyer has served as a successful community mental health activitist in San Diego County for over twenty years. Her vitae is listed on the last page of this chapter. Jane has several mentally ill family members (adult, adolescent, child) encompassing a full range of diagnosis and participation in many systems of care: private, public, VA, criminal justice, foster care, Medi-Cal, and with successes in recovery ranging from practicing physicians to homelessness.

Everyone knows a successful community advocate. These people have several things in common: a passion for their cause, a thorough knowledge of their issue, an ability to articulate, and a well developed network of support to help accomplish their goals. A mental health advocate is no different; the focus is on helping to improve mental health services so that clients can work toward their own recovery. How do you decide if you want to be a community advocate in mental health and how do you get there?

As you advocate on behalf of your own family member you will become painfully aware of many of the needs of your local mental health system.

As you advocate on behalf of your own family member you will become painfully aware of many of the needs of your local mental health system, not to mention state and nationwide. Using the abilities you've developed to assess and advocate on behalf of your own family member, you may now want to extend your efforts to raise the quality of the mental health system. This can be the most rewarding thing you've ever done, but be aware that the learning curve can take some time.

The first thing you will want to do is narrow down your goals (there is so much to do it can become a life's work). Perhaps you will want to concentrate on what is most urgent, both to you and to your family, otherwise you will find yourself pulled in multiple directions by the many issues needing attention. It is helpful to go over your goals with people in your life who support you. What are your skills and inclinations? Do you want to work the political arena? Do you want to work in the trenches helping the clients directly? Do you want to work on improving local mental health programs? You will have to integrate your decision with what is deficient in the system, and develop a plan of attack. Later if you are feeling discouraged in your advocacy, go back to the early statement of your goals and talents to reaffirm your commitment.

This is the time to begin recruiting others with the same goals, but not necessarily the same talents. Look to other family members, clients and professionals who have your same concerns. Choose only those who believe in the ability of clients to work toward

recovery. Otherwise you will end up with major philosophical differences that will destroy your network. Remember, not everyone will be able to spend as much time and energy as you would like, but everyone can do something, even if they are housebound: stuff envelopes, make phone tree calls, write letters, call legislators, do research. If possible, save powerhouse people for presentations to the Board of Supervisors or other governing bodies, one-on-one conversations with mental health administrators and providers, or critical committees. Continue to mentor and train others. What if you get hit by a truck?

The most important skill you must develop is that of listening.

The most important skill you must develop is that of listening. To everyone. To clients and family members. They know what works, they have the street knowledge you cannot get anywhere else. Professionals and contract providers will tell you what is available, what services could fill the gaps, what would be available if there was enough money, how the system hamstrings their ability to deliver services. Administrators will tell you the ins and outs of getting the money and the internal cooperation to develop and maintain services. Public demands will tell you what drives the politicians who control the money. Above all you must generate the patience to continually ask questions and listen to the answers. This will also help you develop a historical perspective of how your mental health system got where it is today. Learn history's lessons. Save yourself from suggesting what turned out previously to be non-productive solutions or downright disasters.

Once you have a good handle on the global situation, your passion may tempt you to go all out to change the system. You must assess your own abilities and staying power. Remember that you can indeed change the system in many small ways. You do not have to attack city hall. To get started, consider how to enlarge the effort that you have been expending for your family member. For example, perhaps you could advocate a change in the program or living situation that he/she is involved in. The most direct and potentially successful way to do this is to pitch in and offer your

help. You will accomplish many things this way. You will begin to establish your credibility. You will develop allies. You will learn more about the system. You will gain the experience and satisfaction of actually improving the system. Usually you will find that your family member is proud of your dedication and accomplishments, and may become more aware of your caring about him/her. If it turns out that the proximity of your involvement makes your family member uncomfortable (and it may) find a different venue.

One of the toughest calls is when and how to speak up and when to remain silent.

You may find that this is quite enough for you -a match with your resources and stamina. Do not be ashamed to pause at this point. Remember that system improvement is an ongoing process and a culmination of the small and continuous efforts of many. It is rare that one person alone can move that mountain. Allowing yourself to reach meltdown is counterproductive. It seldom achieves the goal leaving you discouraged and depressed. You have to maintain your own strength in order to contribute so you should constantly assess yourself— allow yourself to take a sabbatical even for a day. Recharge and renew.

Consider where to find current information and allies if you want to move on. Trust your instincts about things needing improvement (be sure to research what is already being done), and join coalitions that are focusing on improving mental health in your locale. Get on committees that are addressing what is of particular interest to you such as: housing, legislation, access, etc. Warning: when people see you are serious about your commitment, you will be deluged with requests to work on many issues. Resist the temptation to respond to every request that gets you on yet another committee (but try not to lose touch with the big picture). Husband your strength—- *learn to say no*.

You must at every turn develop and maintain your credibility or all your hard work will be for naught. One of the toughest calls is when and how to speak up and when to remain silent. You do this by keeping informed, by listening to others with an open mind, by

analyzing and taking a reality check on your conclusions, and finally by responding firmly (but politely) and bravely. A tall order. You will make mistakes. You will sound foolish at times. Try not to let that dissuade you. Do not be afraid to say, "I don't know." Be quick to apologize when it's in order. Recognize the burdens of others. Be as willing to support as to criticize. Stay human.

Professionals and administrators have discovered that experienced people like ourselves have much to offer, especially in the field of advocacy.

Consider yourself a role model for others who might become advocates. This is particularly true in the case of families. For many years, families have been dismissed as uninformed, over-emotional, incompetent, even destructive. We have to keep working hard to overcome this, and lately much has been accomplished. Professionals and administrators have discovered that experienced people like ourselves have much to offer, especially in the field of advocacy. And many many times we are able to say things in public that they dare not say (and hope somebody will).

Do the basics: seek out and adopt a mentor. Be polite. Know Roberts rules of order. Show up on time. Be considerate of other peoples problems and limitations. Know your subject before you speak out. Do not ramble. Say thank you. Keep your war stories to a minimum. Use them only as brief examples.

Negotiation and compromise are the core of achieving change. It is sometimes hard to maintain your patience and politeness with those who hold the power strings, but you must keep your eye on the prize. Remind yourself that this is still America, and you have a right to speak your mind and stand up for the truth. Many times your greatest challenges will be with those who are trying to maintain the status quo. Your greatest enemy will be their personal agenda. You must be painfully honest with yourself as well, examining *your* agenda and discovering if you are just being stubborn or if you are actually accomplishing something. You will need to be vigilant about being used for someone else's agenda. Ask yourself, "Is the trade-off worth it?" "Am I compromising my integrity?" Often you will find yourself allying with people you may never seek to have as friends, but can still work with toward a common goal even for different reasons.

What are the rewards? Watching someone you know and love benefit from your direct effort is an incredibly joyous feeling. Even the smallest overall system change or accomplishment will bring you a shot of conviction to go on because you will know that somewhere at least one mental health client or family member is being helped, and that the ripple in the pond has begun for many more to be helped. In your own personal life you will develop an increasing sense of proportion about what is important. Some of life's irritating trivia will just evaporate because you simply will not have time for it. When a bigger project is undertaken and becomes reality (usually with others like yourself), the feeling that accompanies the knowledge of really making a difference cannot be matched.

When a bigger project is undertaken and becomes reality (usually with others like yourself), the feeling that accompanies the knowledge of really making a difference cannot be matched.

And great things can be accomplished. In San Diego County, for example, a small group of client and family advocates worked against all odds for several years to promote the idea of an Office of Mental Health Consumer Affairs. After pounding on the table and on the denizens of the system at every opportunity, the concept and its funding was memorialized by being included in the County's request for a proposal to hire a private administrative service organization to manage the local mental health system. When the Director of Health & Human Services heard about it (through the efforts of the advocates), he decided to expand the concept to include all the managed care public health in San Diego County. Several more years of negotiation and advocacy resulted in the founding of a Consumer Center for Health Education & Advocacy, which serves both physical and mental health (the only such in the entire nation).

As Margaret Mead said, *"Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has."*

Guidelines for the Community Advocate

Listen.

Be willing to put in the time to get to the bottom of things.

Constantly examine agendas—yours and other people's.

Be open to new ideas; be willing to abandon a bad idea.

Don't waste time on a lost cause (for now).

Be willing to support as well as criticize.

Speak with candor, deliberation, and from knowledge.

Recognize and cultivate the powerful.

Know when you are being used; evaluate if it's worth it in order to reach your goal.

Get help especially with the volunteer labor. Everyone can do something.

Take care of yourself so you can take care of others.

Never give up.

Pass the torch.

Jane Fyer, married to Leo Fyer for 29 years, 6 children, lives in Del Mar, California, and is President of SEDICO, Inc, an industrial electrical engineering consulting firm. She is also involved in advocacy surrounding environmental issues and community development. She was the Mental Health Person of the Year, 1991.

Current Mental Health commitments:

President, Schizophrenics In Transition-AMI (NAMI-SIT)

Acting Director, Creative Arts Consortium

Co-Chair, Consumer Center for Health Education & Advocacy Advisory Board

Vice Chair, Healthy San Diego Consumer Advisory Committee

Chair, Healthy San Diego Sub-Committee for Consumer Education & Advocacy

Vice President, San Diego County Psychiatric Hospital Auxiliary

Chair, San Diego Community College District Community Advisory on Disabilities

Co-Chair, United Behavioral Health Quality Assurance Advisory Committee

Treasurer, Clients & Others For Action (COFA)

Member, United Behavioral Health/San Diego County Performance Outcome Committee

Member, San Diego County Mental Health Managed Care Advisory Group

Member, San Diego Coalition for Mental Health Sub Committee on Housing

Member, San Diego County Consumer Council on Mental Health

Other (past) positions in Mental Health:

Chair, San Diego Coalition for Mental Health (founding member)

President, San Diego County Psychiatric Hospital Auxiliary

Chair, Client & Family Advisory Board to Intensive Case Management Program

Chair, Mental Health Recognition Dinner Committee

Member, North Coastal AMI Board of Directors (AOR: Advocacy & Action)

Chapter 13

Thoughts on Grief

Donna Linz is a therapist in private practice on Bainbridge Island, Washington. This information about the process of grieving is part of a workshop she has created for family members of those who suffer from serious mental illness.

Some Thoughts on Grief

Grief is the process by which we heal from loss. Loss can take many forms and is felt on many levels.

We experience grief in our thoughts, feelings, and bodies.

There is no one right way to grieve. How we each experience grief is influenced by many factors including personality style, cultural norms, physical and emotional health, spiritual beliefs, family relationships, etc.

We experience grief in our thoughts, feelings, and bodies.

Thoughts may include: Why?, Why them?, Why me?, If only . . ., What if?, I wish . . ., etc. **Feelings** may include anger, fear, shame, anxiety, worry, disappointment, sadness, depression, guilt, isolation, hopelessness, despair, etc. **Physical sensations** may include headaches, tension, tightness, pressure, GI distress, muscle aches, difficulty breathing, fatigue, low energy, difficulty concentrating, sleep and appetite disturbance, and a vague or unresolved sense of illness that has not responded to medical attention.

Grief is a cyclical rather than linear process, meaning that it may recycle periodically when something in your life reminds you of your loss. However, the intensity, duration, and severity of the cycles diminishes over time and becomes less debilitating and overwhelming when you allow yourself to express it in healthy ways.

While we each experience grief in our own unique way, there are typical stages which seem to characterize the process. These include:

1. Shock, denial, disbelief
2. Anger, rage, "It isn't fair!!"
3. Bargaining- The "What if", "If only's", "why's"
4. Depression, sadness
5. Adjustment, coping, acceptance

More often than not, these cycles repeat or recycle from time to time, and may not necessarily occur in the above order.

The goal is to recognize when you are recycling a piece of grief. As you become aware, you can do several healthy things.

The goal is to recognize when you are recycling a piece of grief. As you become aware, you can then do several healthy things. The most important is to simply acknowledge that you are feeling grief, anger, or sadness, and to allow time for this. You don't have to do anything. Just give yourself permission to feel what you are feeling. Next ask yourself, "What can I do to help myself feel better for now?" Become very skilled at knowing what renews, heals, nurtures and replenishes you in healthy ways. Make a list of these things so you can refer to it when you are distressed.

If you are experiencing more than two of the following characteristics, you may be stuck in acute grief. Please seek out a professional counselor to help you through this time.

- You find you are not sleeping (or sleeping too much).
- You are not eating (or eating too much).
- You have feelings of hopelessness and despair.
- You find it difficult to accomplish your daily routine for more than a couple of weeks.
- You find anger coming to the surface without cause, or you are confused about the anger you are feeling.

This material prepared by Donna Linz, MSW. Questions or comments can be directed to her at (206) 842-2323.

Chapter 14

Begin Healing

Healing comes about when we restore ourselves. To restore means to mend, rebuild, recover, revive, strengthen and bring back to health. In this section we will discuss ways that will help us, our ill relative, and our whole family begin the processes that can lead to healing.

Begin Healing

To begin healing to some of us may be a relief. To others it may seem impossible after all the hurt we have experienced. These biological brain disorders bring an earthquake to families. Nothing is ever the same again. These illnesses shake us down to our foundations. Our family is changed forever, but we can begin the healing process.

The contributions in this section come from a variety of sources. David Richo's article "Maintaining Personal Boundaries in Relationships" gives us solid advice about how to establish and maintain our own "self" in the midst of the traumas that we experience.

"Healthy Pleasures", and "The Virtues of Sensuality" are contributed by Scripps Well Being Clinic in San Diego, California. When we advocate, we must take good care of ourselves. These ideas from Scripps will help us to do that.

"What Parents Can Do for Siblings," and "Notes for Siblings/ Adult Children," are both written by Rex Dickens. Rex is one of the founders of the National Alliance for the Mentally Ill Sibling and Adult Children's Support Network. He teaches us about some of the ways that siblings and adult children of persons with brain disorders feel about their own experiences.

Education about the illness and how it affects my brother and our family has been the most important ingredient in my own healing. Understanding and abiding by my personal boundaries while moving on to create the life that I want is the key to happiness for me.

Maintaining Personal Boundaries in Relationships

by David Richo

Our journey began at birth with no sense of boundaries. We did not understand where we ended and others began. Our overriding desire was to fulfill our own needs.

At our first realization of separateness, our task was to acknowledge our personal boundary. I am separate and so are those who care about me. This was a departure and a struggle.

It may have felt like abandonment. From the beginning of life, we may have equated letting go of attachment with loss of power and security.

The mystery about why we hold on so fiercely today may stem from this original terrifying and illusory event.

Adults learn that separateness is not abandonment but simply a human condition. The only condition from which a healthy relationship can grow.

I know I have lost my boundaries and become co-dependent when: "I don't let go of what doesn't work" and it feels like "I can't let go of what could work." Co-dependency is unconditional love for someone else that has turned against oneself.

With boundaries comes interdependence rather than dependence. With boundaries comes personal accountability, not entitlement to be taken care of unilaterally. From boundaries comes the mutuality that exchanges control of another in favor of honor of another.

Boundaries do not create alienation; they safeguard contiguity. Boundaries are what makes it possible for us to have closeness while we safely maintain a personal identify.

Giving up personal boundaries means abandoning ourselves! No relationship can thrive when one or both partners forsake the unique core of his/her own separate identity. Love happens when two liberties embrace, salute, and foster one another.

In a healthy person, loyalty has its limits and unconditional love can coexist with conditional involvement. Unconditional does not, after all, mean uncritical. You can both love someone unconditionally and place conditions upon your interactions to protect your own boundaries. "I love you unconditionally and I take care of myself by not living with you." This is shrewd fondness!

The essential inner core of yourself must remain intact as relationships begin, change, or end. The journey never violates our wholeness. When you are clear about your personal boundaries, the innate identity that is you is not bestowed by others nor do you let it be plundered by them.

It is building a functional healthy ego to relate intimately to others with full and generous openness while your own wholeness still remains inviolate. It is a great boost to self-esteem to be in touch and intact. This is adult interdependence.

How to maintain your personal boundaries:

Your personal boundaries protect the inner core of your identity and your right to choices: "There lives the dearest freshest deep-down things." *— Gerard Manley Hopkins*

Ask directly for what you want. This declares your identity to others and to yourself.

Foster inner self-nurturance (a good parent within oneself). This builds an inner intuitive sense that lets you know when a relationship has become hurtful, abusive, or invasive. It is built as a result of the work you do on your childhood issues. The ongoing support of honest feedback from friends, self-help programs, or therapy will help maintain self-nurturance.

Observe the behavior of others toward you - taking it as information - without getting caught in their drama. Be a fair witness who observes from a self-protected place. This is honoring your own boundaries. It empowers you to decide — uninfluenced by another's seductive or aggressive power — how much you will accept of what someone offers you or of what someone fires at you.

Maintain a bottom line. A limit to how many times you allow someone to say no, lie, disappoint, or betray you before you will admit the painful reality and move on. This includes confronting addiction and/or futureless relationships in which you continue to look for happiness where there is only hurt. In addiction, our illusory belief compensates for the diminished reality.

Change the locus of trust from others to oneself. As an adult you are not looking for someone you can trust absolutely. Acknowledge the margins of human failing and let go of expecting security. You then trust yourself to be able to receive love and handle hurt, to receive trustworthiness and handle betrayal, to receive intimacy and handle rejection.

A Checklist on Boundaries in a Relationship

When you give up your boundaries in a relationship you:	When your boundaries are intact in a relationship you:
Are unclear about your preferences	Have clear preferences and act upon them
Do not notice unhappiness since ending is your concern	Recognize when you are happy / unhappy
Alter your behavior, plans, or opinions to fit the current moods or circumstances of another (live reactively)	Acknowledge moods and circumstances around you while remaining centered (live actively)
Do more and more for less and less	Do more when that gets results
Take as truth the most recent opinion you have heard	Trust your own intuition while being open to other's opinions
Live hopefully while waiting and wishing	Live optimistically while overseeing an change
Are satisfied if you are coping and surviving	Are only satisfied if you are thriving
Let that other's minimal improvement maintain your stalemate	Are encouraged by sincere, ongoing change for the better
Have few hobbies because you have no attention span for self-directed activity	Have excited interest in self-enhancing hobbies and projects
Make exceptions for a person for things you would not tolerate in anyone else / accept alibis	Have a personal standard, albeit flexible that applies to everyone and asks for accountability
Are manipulated by flattery so that you lose objectivity	Appreciate feedback and can distinguish it from attempts to manipulate
Try to create intimacy with a manipulator	Relate only to partners with whom mutual love is possible
Are so strongly affected by another that obsession results	Are strongly affected by your partner's behavior and take it as information
Will forsake every personal limit to get sex or the promise of it	Integrate sex so that you can enjoy it but never at the cost of your integrity
See your partner as causing your excitement	See your partner as stimulating your excitement
Feel hurt and victimized but not angry	Let yourself feel anger, say "ouch" and embark upon a program of change
Act out of compliance and compromise	Act out of agreement and negotiation
Do favors that you inwardly resist (cannot say no)	Only do favors you choose to do (you can say no)
Disregard intuition in favor of wishes	Honor intuitions and distinguish them from wishes
Allow your partner to abuse your children or friends	Insist others' boundaries be safe as your own
Mostly feel afraid and ashamed	Mostly feel secure and clear
Are enmeshed in a drama that is beyond your control	Are always aware of choices
Are living a life that is not yours, and that seems unbearable	Are living a life that mostly approximates what you always wanted for your self
Commit yourself to: as long as the other needs you to be committed (no bottom line)	Decide how, to what extent, and how long you will be committed
Believe you have no right to secrets	Protect your private matters without having to lie or be accountable

By David Richo - Author of "How to be an Adult: A Handbook on Psychological and Spiritual Integration" Paulist Press 1991

Healthy Pleasures

One of the strongest predictors of future health and longevity is self-reported health and health optimism.

Depression and the number of years of education may be a better predictor of future heart problems than high cholesterol or smoking.

People who cultivate many different aspects of themselves through work, hobbies, interests, and relationships appear to be more immune to stress.

Healthy people have a set of positive ILLUSIONS about themselves and their lives which sustain them, filter out adversity, and give the world a rosy glow.

Vacations are a vital part of self-renewal and can reduce fatigue, digestive problems, insomnia, and loss of interest in sex by 50%.

Laughing is a form of "inner jogging. " Laughing raises pain threshold, boosts the immune function and protects against stress. Watching a Richard Pryor Live tape increases antibodies in saliva that may help defend against infections like colds.

A good cry produces tears that may rid the body of stress related chemicals thereby helping to restore physiological and emotional balance.

Caring for and about something outside of yourself whether it be people, plants, or pets, may enhance health.

Men who do regular volunteer work have death rates two and a half times lower than those who do not commit themselves to such community activities.

Heavy consumption of alcohol damages both mind and body. Those who imbibe moderately (2–3 drinks per week) have nearly half the heart disease risk of heavy drinkers or teetotalers.

The great surprise of human evolution may be that the highest form of selfishness is selflessness.

Wishing you healthy pleasures, and healthy lives! For more information call Scripps Health Community Health and Oureach Services/THE WELL BEING 1-800-SCRIPPS.

The Virtues of Sensuality

Happiness appears to come from enjoying small daily pleasures: listening to a favorite piece of music, playing with your cat, a hug, a compliment from your boss, a delicious meal, etc..

A brief stay in the heat of a sauna may trigger the release of endorphins, the body's pain relievers, and bolster immunity to colds and other infections. Children taking a weekly sauna had half as many days missed from school due to infections.

Gazing at fish in an aquarium can measurably lower blood pressure as well as reduce pain and anxiety in patients facing a dental extraction.

Modern aromatherapy finds that certain fragrances, like spiced-apple can reduce the stress response. Blood pressure declines, breathing slows, muscles relax, heart rate slows, and mood improves.

When people with chronic anxiety are given massages, their physiological reaction to stress is blunted, their symptoms decrease and their use of medication declines.

For some people, depression, dark moods, withdrawal, lethargy, and declining sex drive are symptoms of lack of light. This can be reversed by exposure to sunlight or bright lights.

The 'no pain, no gain' exercise slogan is simply wrong. The biggest health gains come with the least pain and from gentle pleasurable pursuits such as dancing, gardening, walking, or playing with children.

The napless day is probably an unnatural, fairly recent innovation. We probably evolved accustomed to an afternoon rest. One study showed that men taking afternoon siestas had a 33 to 50% less chance of having a heart attack.

Eating hot chili peppers appears to boost metabolic rates. Burning extra calories prevents blood clots and may even lower blood cholesterol.

Shopping is the modern day version of the hunting and gathering behaviors that sustained our early ancestors. Recreational shopping may dispel boredom, lift spirits, quell loneliness, and provide an opportunity to live out fantasies.

Scripps Health – Wishing you "healthy pleasures, and healthy lives" . . .

Take Care of the Caregiver

Dedicated to those family members and friends who are primary caregivers of a loved one or friend with mental illness.

1. Be gentle with yourself.
2. Remind yourself that you are a loving helper, not a magician. None of us can change anyone else—we can only change the way that we relate to others.
3. Find a place where you can be a hermit. Make use of it everyday or when needed.
4. Learn to give support, praise and encouragement to those about you. Learn to accept it in return.
5. Remember that in the light of all the pain we see around us we are bound to feel helpless at times. We need to be able to admit this without shame. Just in caring and in being there we are doing something important.
6. Learn to vary your routine often and to change your tasks whenever possible.
7. Learn to know the difference between complaining that relieves tension and complaining that reinforces it.
8. On your way home from work focus on one good thing that happened during the day.
9. Become a resource to yourself! Be creative and open to new approaches to old things.
10. Use the support you give to others or a "buddy" system regularly. Use these as a support for reassurance and to redirect yourself.
11. Avoid "shop talk" during your breaks or when you are socializing with colleagues.
12. Learn to use the expression "I choose to . . ." rather than expressions like "I have to . . .," "I ought to . . .," or "I should . . ."
13. Learn to say "I won't . . ." rather than "I can't . . ."

14. Learn to say "no" and mean it. If you can't say "no"- what is your "yes" worth?
15. Aloofness and indifference are far more harmful than admitting to an inability to do more.
16. Above all else-learn to laugh and to play.

— *Author Unknown*

What Parents Can Do for Siblings

by Rex Dickens

What Parents Cannot Do

1. Cannot take away the fact that mental illness impacts their other children.
2. Cannot lessen the impact by not talking about it.
3. Cannot shield the other children from their own feelings about it.
4. Cannot determine the coping style each child may adopt.
5. Cannot do the grieving (mourning) process for them. This involves denial, sadness, anger, and finally acceptance, with each person going through this process in his own way at his own pace.
6. Cannot make them seek help if they need the denial stage.
7. Cannot take away peer and societal stigma.
8. Cannot expect they will not have a variety of negative emotions such as guilt, fear, grief, resentment, and jealousy.

What Parents Can Do

1. Be aware that all family members are profoundly affected.
2. Be aware of the coping stance their well children adopt, for example, estrangement, enmeshment, etc.
3. Talk about your feelings and encourage them to do the same.

4. Learn about the illness to lower the family anxiety.
5. Do not make the ill member the axis around which the family revolves. This is as detrimental to the ill person as it is to the other family members!
6. Seek to improve the mental health system so that aftercare options are available.
7. Read some sibling articles and books to gain a background understanding of the sibling experience.
8. Help make your children aware of the Sibling and Adult Children's Network and the quarterly newsletter, "The Bond," if and when they are emotionally receptive.

Wrap-up

In previous workshops there have always been a few people who leave saying 'We've tried and nothing has worked'.

Initially I have to ask these basic questions:

Have you written a historical chronology?

Have you viewed the facilities that you encounter as a resource for you and your family?

If you feel you need time with a counselor for yourself, have you asked for it?

Have you asked a counselor on staff to sit down with you and your relative?

Estrangement encompasses a loss of affection, alienation, emotional distancing and withdrawal. All of these can result from a lack of communication.

I have talked to hundreds of family members over the years about how mental illness has affected us. A common problem we have all faced is a breakdown in communication. When these breakdowns are not acknowledged and corrected, estrangement can result.

Estrangement encompasses a loss of affection, alienation, emotional distancing and withdrawal. All of these can result from a lack of communication.

When my brother turned sixteen, because of his symptoms, I believe, he became very defiant of those in authority. Of course this included our parents. He was the oldest boy at home with three younger sisters. This order of birth placed him in a position of leadership in the family that he was not necessarily able to cope with. No one was to blame because none of us were aware of the symptoms he was experiencing. Our expectations simply exceeded his abilities at the time. He seemed unable to give in to parental authority.

Looking back, we realize that this type of behavior set the background for his later paranoia. Our ability to judge is an important skill that we all need to hone and mature. Although my

When we can trust again and feel safe, the healing process can begin within our family.

brother maintained many other skills he was simply not equipped to handle mature personal relationships. Sometimes, when his decisions or judgement brought him into some predicament, he had no contrition for how he affected others.

I think this is the quality that a parent often finds hard to understand. Problems in communication and relationships may lead to isolation and estrangement within our families. We need to educate ourselves about mental illness before we can talk about the illness and try to understand how it affects all of us. We realized in our family that the effect of the mental illness changed the way we communicated over a period of years and it will take some time and effort to heal.

Estrangement becomes an obstacle to recovery and must be repaired before we can establish a mutual trusting relationship which includes all of our family members. When we can trust again and feel safe, the healing process can begin within our family.

If this sounds familiar to you, talk with each other and if it doesn't work, ask a professional for some help so that you can learn to communicate your feelings with each other. Sometimes all that is needed is a simple "I'm sorry, let's begin again."

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