Windhorse Community Services

Home-Based Recovery of Mental Health

Windhorse Guide for Families

By Constance Packard, MSW

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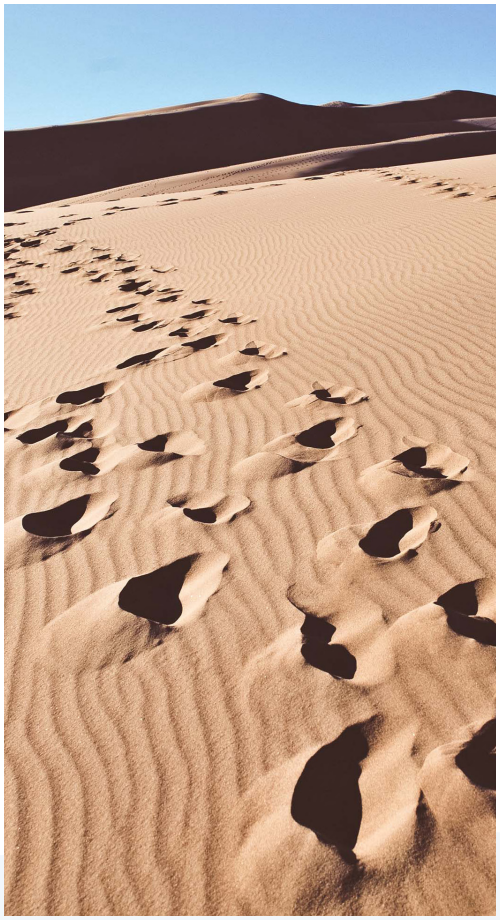


This is a guide for families who have a member suffering from a major mental disturbance, such as schizophrenia, bipolar disorder or severe depression. The basic text was written by **Constance Packard, M.S.W.** She is the mother of a son with a diagnosis of schizophrenia, a family therapist and a member of the Windhorse Board of Directors.

Windhorse is a coalition of professionals, consumers, and family members, and we consider it very important that these three groups work together in a way which informs the whole. Therefore, the clinical staff went through a process of revising and refining the guide, with special input from **Sally Clay** and **Harold Raush**. Sally is a consumer/survivor activist who was, at the time, both on the staff and a member of the Board of Directors. Harold is the father of a Windhorse graduate, a clinical psychologist and co-leads the family program.

We offer the Guide as an introduction to the way we at Windhorse Associates work with the families of our clients. We also offer it to other families anywhere who may find it helpful.

Introduction

Mental health professionals used to tell us that parents caused mental disturbance in their children. Students of psychiatry, clinical psychology and social work learned about "schizophrenogenic mothers" and distant fathers. Fortunately, that belief concerning the cause of mental illness no longer holds sway. At present, the predominant view in the field is that mental disturbance is a physical illness in which thoughts and behaviors are symptoms of an imbalance in the brain. Mental illness is compared to a disease such as diabetes. We are told that something is defective and can only be "fixed" through medical technology such as drugs. This view is often called the "medical model."

The implication of this view is that if there is a defect in the brain, then there is no hope of recovery, and the best we can do is manage symptoms. The medical model requires a constant vigilance for the reappearance of symptoms and encourages a tendency to find something "wrong" in the slightest change in attitude or behavior. In addition, if families and professionals rely solely on the medical model, we tend to give messages that dis-empower those who suffer from these conditions.

The Windhorse approach is quite different. We view mental affliction as essentially a human problem that can best be addressed through human means. While there are many factors involved in mental disturbances, including brain function and heredity, we do not regard the person as an illness, or a bundle of symptoms. Instead we deal with the problems at hand with common sense—with respect, discipline, kindness and lifestyle choices. We work to create a physical and psychological environment that benefits everyone who lives within it—both the person in difficulty and his or her family and friends.

We believe that recovery is possible, and that we can emerge from the suffering and confusion of mental disturbances with a depth of understanding that will stand us in good stead for the rest of our lives. We believe that it is possible to have a meaningful life, in spite of disability, all along the path of recovery and whether or not full recovery occurs.

We include families in our work because family dynamics, attitudes and communication do affect the recovery process, either giving impetus to recovery as part of creating a "sane environment" or impeding it. Family

members are deeply and powerfully interconnected. If one member of a family is in an extreme state, all members of the family will most likely find that they are also in an extreme state of some kind in response to the difficult situation and the intense emotions associated with it. The on-going disruption, grief and anxiety experienced by families, combined with negative cultural attitudes towards mental illness and a fragmented mental health system, constitute major and continuous stresses of many kinds on many fronts. We know that it is a difficult journey, and that all of you have at times been stretched to the limits of your endurance. We know that families, as well as clients, commonly find themselves in a dark labyrinth of grief, fear, conflict and confusion - and that it is hard to know where to turn for guidance.

No matter how great the stress or turmoil, in our experience there are two basic concerns closest to the hearts of most family members: 1) How can I give my son or daughter, sister or brother, husband or wife what he or she needs from me? 2) How can I and the other members of our family survive and flourish in the midst of all this chaos and heartbreak? These are the two basic concerns to be addressed in thinking about the family situation and how to help. They are completely interrelated and interdependent and cannot really be addressed separately, because the ability of family members to give their mentally disturbed relative what he or she needs from them will be greatly enhanced if they themselves have attained a degree of equanimity and are leading satisfying lives.

In fact, the interconnectedness of these two concerns is an important principle underlying all our work and also extends to the network of professionals and team members involved in the client's treatment. Stated in another way, the first principle guiding our work is that the client, the professionals and significant family members are all inextricably and closely linked in the recovery process and that everything affects everything else, for better or for worse. Consequently, it is of great importance that we all work together with a common purpose and a common vision of what promotes recovery. Through our combined experience as professionals, family members and recovered consumers, we have learned some guiding principles for families that lead toward healing and recovery. It is these five principles that we present here and which we believe enable us to give our family member the support and nurturing he or she needs, to set boundaries and limits to protect everybody in the family and to find the space to nurture ourselves—all necessary requirements if the family is going to function for the benefit of all its members.

I ATTITUDE

Cultivate Acceptance and Respect

Attitude is key in the healing process. It is impossible to overstress the importance of an accepting attitude on the part of family members. Mental disturbance almost always seems to bring with it crippling self-doubt and low self-esteem. These are all too often reinforced by the stigma encountered in many ways in our society. An attitude of unconditional respect and acceptance, therefore, from those who are closest to the client is the ground from which recovery can begin. This means accepting our relative exactly as he or she is at present. It means seeing all of his or her beauty and strength and good qualities. It means letting go of our expectations that our relative should be any different than he or she is right now.

Looking at the situation solely from the point of view of the medical model makes this extremely difficult, if not impossible, to achieve. For if we view our family member as sick and want him or her to get well, which implies change, we must think about the message we will be giving. The message will be that our son, for example, is not okay the way he is and must become something different in order to get our acceptance. If we relate to him as if his words and actions have little or no meaning because they are the result of a chemical imbalance, what message are we giving? We are giving the message that he cannot trust his own mind, thoughts and feelings, and that we do not trust them very much either. Though we don't intend it, these messages come across as critical and disrespectful. This can only reinforce our family member's very painful feelings of despair, frustration, anger and self-doubt. If these subtle and not so subtle messages are coming from both families and professionals, it becomes much harder for people in these difficult states of mind to trust themselves or others. The ability to trust oneself and important others is a key ingredient in recovery.

How is it possible to give up our dreams and expectations that our family member must have a normal life with normal achievements? This can be a painful process and can take years of being worn down by failures, disappointments and setbacks. It is important to remember, however, that one's attitude is a matter of choice. One can choose to adopt an attitude of unconditional respect and acceptance -- yet to do so requires letting go of most of our cultural conditioning. We are conditioned to see mental illness as pathology and as tragedy. Almost all of

the literature and professional opinion describe it this way. Our society's emphasis on achievement and status reinforce this view. To let go of all of this requires a radical shift to a very different way of seeing things. It requires seeing the person as whole and perfect as he or she is. It requires cultivation of a nonjudgmental stance in recognition of our inability to know the whole truth about anything. It requires trust that our experience and the experience of mental illness have meaning, regardless of the outcome. It requires acknowledgment that we are each in charge of our own path in life. It is a point of view that chooses to see the gift hidden in each challenge.

For example, when we talk to our son or daughter, we address their inner quality of humanness rather than their outward appearance or diagnosis. Let us say my daughter exhibits some strange or disturbing behavior. My first reaction may be to ask her if she is getting sick again, and urge her to take her medication. If I say this to her, she will probably regard it as an accusation and withdraw further into mistrust.

Instead, I listen respectfully to what she has to say, with my mind open to appreciate her intentions and to follow her thought processes. I may honestly say that I do not agree with her, or that I find what she says to be impossible. But if I have truly listened, my daughter will trust that I want to understand and that I do not reject her as an adult person. The process of listening itself may serve to open the doors of communication and may lead to new avenues of thought that will make sense to both of us.

The by-product of mutual respect is that nobody needs to feel under pressure to be anything other than who they are. My daughter will feel free to talk openly to me. She need not feel that she is not acceptable unless she denies her feelings and beliefs. At the same time, I do not need to feel guilt that I have caused some terrible catastrophe. My daughter is not a catastrophe; she is someone I love and respect for who she is.

The unconditional part of respect is the way we value the person behind the symptoms, in spite of the mistakes, and along with the confusion. We do not need to ignore or deny the symptoms, the mistakes and the confusion. Our family member can work on symptoms at his or her own pace, with a sense of relaxation.

Unconditional respect provides a backdrop of hope and acceptance. This attitude of acceptance of our family member is, paradoxically, the attitude on the part of families and caregivers that is most conducive to promoting change. Just as it is a

paradox that when we are able to accept ourselves as we are, we are freer to direct energy toward what we might want to change in our lives.

Yet this attitude is a very difficult balance to achieve, because of course we all would like to see our family member happier and having the life he or she desires. The attitude toward our clients we work to cultivate is an attitude of wanting change for them but of not needing them to change. It combines respecting and accepting wherever they are at any given moment—psychotic thinking, altered awareness, difficult behavior and all –with holding out hope and the possibility of change, and at the same time non-attachment to the outcome. This requires humor, patience and a light-handed approach rather than a heavy one. A tall order! Yet we have everything to gain and nothing to lose in reaching for it.

II ORIENTATION

Choose Happiness

As stated above, having a relative who is suffering serious mental disturbance places a great strain on families. The cultural attitude, which we have inherited, views mental illness as a tragedy, and stigma is still common. The normal tendency in such a situation is to focus on the "sick" member and to try somehow to bring about change in him or her. The reality is, however, that we do not have the power to change anybody else -- we have only the power to change our own behavior and attitudes. When we put pressure on someone else to change, the normal reaction for that person is to resist in order to retain his or her autonomy. In such a situation, all the energy is bound up in an attempt to influence another's behavior and in resistance to that attempt. Efforts in this mode lead to increasing entrenchment in frustration and a sense of powerlessness. Thus, if the focus is all on the "sick" person changing and not on ourselves and what is happening in the relationships surrounding the individual, it is almost impossible to avoid getting trapped in destructive, repetitive patterns and power struggles.

These unresolved struggles and repetitive patterns lead in a downward spiral to the labyrinth of frustration, fear, grief and guilt where we don't know how or where to set limits and where there is often family disagreement over how to proceed. There is a good chance that in this situation we are "running on empty" and that the whole family atmosphere is pervaded with the heaviness of tragedy and grief. The family's energy and resources are depleted. Everybody's health and welfare are adversely affected. In this atmosphere, it is impossible for the family to function in a way that benefits its members.

In order to get the focus off the "sick" person, it is immensely liberating and helpful to turn the focus inward to ourselves, because that is the terrain over which

we do have control. One's own state of mind is crucial in any healing work.

We have found that the recovery of someone experiencing serious mental disturbance is most likely to happen when everyone in this small healing community is actively engaged in taking care of their own well-being and mental health. That is, they balance their concern for and efforts to help the client with concern for other members of the family and for their own growth and well- being. No matter where we are on the spectrum, we all need the benefits of healing in one area or another. There is always room to become clearer, happier, less fearful and less controlled by past negative conditioning. We believe that one must be happy oneself in order to help alleviate the suffering of anyone else. What heals is the ability to be with another's suffering without judgments and without need at the moment to do anything about it—just simply to connect in empathy with the other's pain, to appreciate and to know something of his or her ordeals. If we are unhappy ourselves, all the thoughts, feelings and beliefs associated with the unhappiness will cloud our minds and will prevent us from being fully present with another's suffering. If there is action to be taken, the unhappiness prevents us from seeing what the most skillful action would be. It is important to point out that if we view mental disturbance as a tragedy, it will be an added burden for our family member. Even in the midst of turmoil, an emotionally disturbed person is aware of the people around him, and of their states of mind. Love does not leave when confusion comes in, and your family member is acutely conscious of how you react to him and of how you feel about yourself. Chances are the person already feels tremendous pain and guilt for being "sick." He is only too well aware that he has turned your household upside down and brought frustration to everyone who lives there. In addition to the other burdens of his condition, will be the belief that he is the cause of your unhappiness. Can you imagine how it must feel when those who know and love you most intimately view you as a tragedy?

Thus, your happiness is of concern to us both for your sake and for the client's sake. The happier and freer you are, the more you will give impetus to your family member's recovery, because the more you will be able to be truly present for him or her. The greatest gift we can give to those who love us is our own happiness. Confidence and lightheartedness are contagious and are always healing to those in trouble. It is important to remind ourselves that just as we can choose our attitude, we can

choose an orientation towards happiness. In fact, the two go together. Finding the time and space to take care of yourselves in whatever ways possible is another of the key interconnected principles guiding out of the labyrinth of suffering.

III BOUNDARIES

Set Limits. Give Space.

All healthy relationships require limits and clear boundaries, but for people experiencing psychosis or other disturbed states, clear limits are especially important. It is often difficult for them to distinguish reality from non-reality and to know where the boundaries of one's self or others are, so it is crucial that family members know how to set limits clearly and firmly for the protection and well-being of everyone in the family. Limits can be internalized but must first be external. They are containers of excitement by saying "this is how far you can go." They give structure, rules, a sense of order and predictability. As acceptance and respect prepare the ground for recovery, clear limits stabilize the ground and help make the client's situation reliable and trustworthy.

Limit setting skills have to do with respecting both our own autonomy and the autonomy of the client. They have to do with accepting and respecting our own feelings, and with taking our own personal needs as seriously as those of the client. They have to do with asserting our right to be comfortable in our own homes. They have to do with making clear "I statements" about what we need, want or expect, rather than blaming and judging statements (which usually start with "you.") Limit setting skills include being prepared to take action to enforce limits if necessary. These are not easy skills to acquire, so we must work on identifying where limits need to be set and on how to set them.

Setting limits also involves setting limits on oneself. For example, it is very common that siblings and spouses feel neglected and unheard because so much attention and intense concern are inevitably drawn to the family member who is disturbed. It is important therefore that parents set limits on themselves by not obsessing too much about one member of the family and by not allowing their lives to be dominated by crises or grief.

IV FULL EXPRESSION

Show Appreciation. Be Honest.

Our clients often have a hard time appreciating themselves, so it is very important that they hear your appreciation of them exactly as they are in the present moment, without need for them to be different. It is important to acknowledge their good qualities and to greet their accomplishments with enthusiasm. This engenders more respect on our part and is empowering. In addition, it is an excellent way to express love. Appreciation and love, warmly expressed by significant others, is the most potent of healing forces.

On the other hand, it is extremely important not to treat the family member with "kid gloves," or to become falsely cheerful, or to attempt to protect the person from everyday frustrations and challenges. To make the mistake of "coddling" the person or to give dishonest praise will only backfire and make the person feel "different" and like a stranger in his or her own home.

The Windhorse approach places great emphasis on honesty in all communication. People who suffer from serious mental disturbance are most often acutely sensitive to the emotional overtones of whatever is being communicated. It is often hard for them to distinguish the line between reality and delusion, so consequently they rely on their antennae to pick up the underlying emotional tone of a message. It is the emotional tone which, after all, is the true message being communicated. Thus, it is crucial that we are mindful of the emotional message we are giving, and that we are sure that the words and their emotional context are congruent.

Both positive and negative honest feedback are important in establishing a trustworthy environment. Appreciation is one aspect of honest feedback. Another aspect is the ability to be honest about one's negative feelings in a non-blaming, non-judgmental constructive manner. The key, again, is mutual respect, for even the bitterest truth is palatable when expressed with graciousness and dignity.

V THE SOCIAL ENVIRONMENT

Find Community

Mental disturbance in a family member takes a heavy toll. It absorbs energy of not only the afflicted person but also of each family member, whether adult or child. Although each member will react in his or her individual way, the illness can readily consume all of the family space. The burdens and challenges of the situation can leave each person feeling isolated and with a sense that his or her own needs are unrecognized. Professional institutions, in their primary concern with the sick member, most often provide little or no support for other family members. It is not only within the family that isolation can occur. The stresses of care taking, and often the sense of stigma that is still associated with mental illness, may lead to withdrawal and isolation from the broader social community.

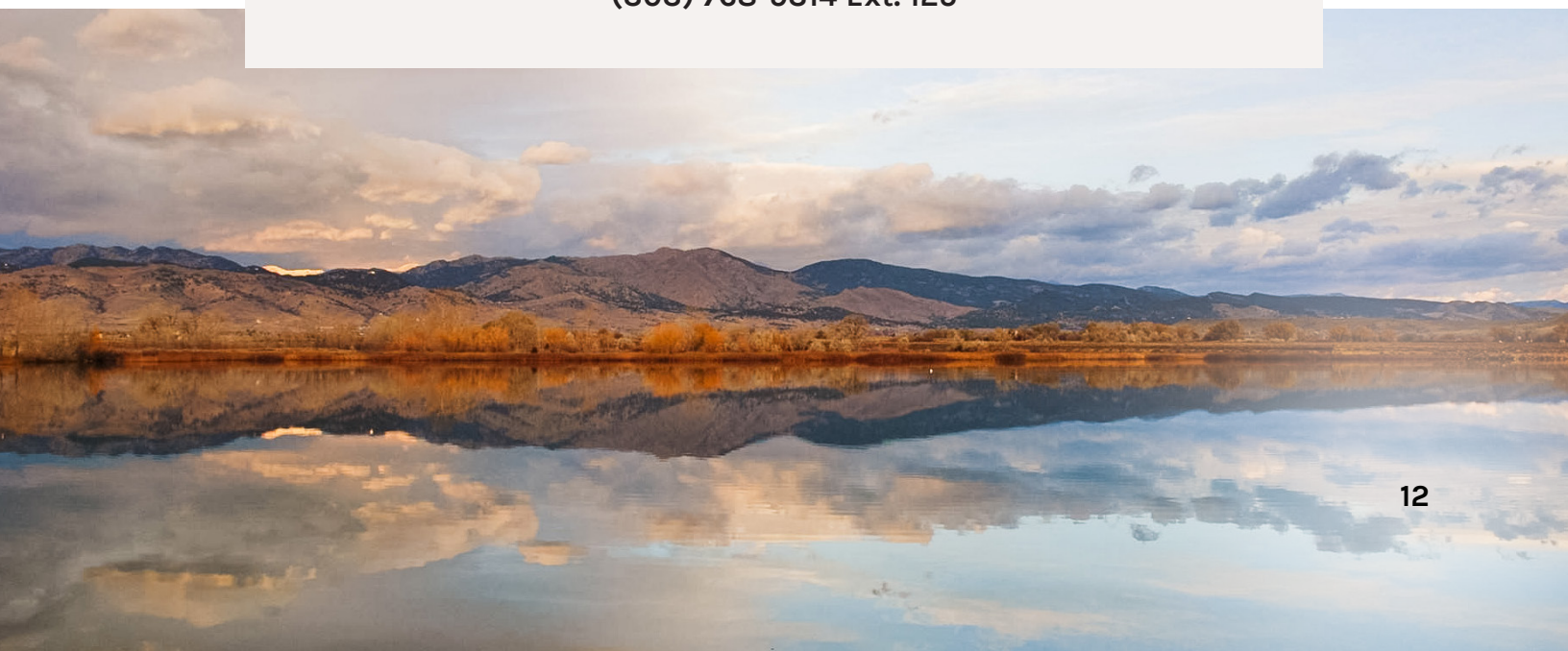
It is especially at this time that the family needs support. Because of the stigma that is sometimes attached to families of mental health clients it may be difficult to be open about the need for support. This need is not a matter of psychotherapy--although that might be useful for some families or family members. What we are referring to here is rather a matter of finding a sustaining environment. Such an environment could consist of other families with similar problems, an environment in which participants can explore and help one another with modes of coping and survival. Or, it could be simply the cultivation of friends who provide resources that reflect the guiding principles discussed above. Families with a mentally ill member can also achieve gratification and enrich their own lives by helping others who are in the same boat. Families differ, and each must find the kind of community resources that will enhance its own capacity for individual and conjoint happiness.

Summary

We see our joint work as "tending" the network of relationships that surround the client the way one tends a garden—carefully and regularly. How is it that tending relationships promotes recovery? Recovering from serious mental disturbance requires great courage and motivation. Love, acceptance, nurturing and respect all evoke motivation and courage. As the network of relationships surrounding the disturbed person is tended, more of the energy required for recovery is available. We have seen that the client's struggle to grow and recover is stimulated by the following: a cheerful and hopeful atmosphere; unconditional acceptance; real exchanges of friendship; honest feedback including expressed appreciation of who he or she is in the present moment; the maintenance of realistic limits for the protection of everyone; and social support. These are the same things that everyone needs from significant others to grow and flourish, so we take these principles as the basis of our work at all levels within the Windhorse community. We see this as the challenge, as the gift that comes along with the suffering involved in these difficult states of mind. For in meeting this difficult challenge, family members (as well as professionals) have the opportunity to find the best in themselves and by expressing it, to live freer and happier lives.

Get in Touch

www.WindhorseCommunityServices.com

admissions@wcsboulder.com

(303) 768-9314 Ext. 125