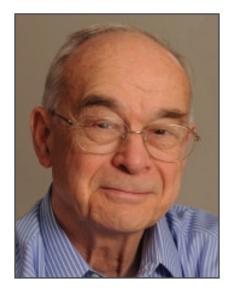


## The BeST Kind of Help: Tools and Tips for Schizophrenia Recovery

Written by individuals with lived experience of schizophrenia in cooperation with the Best Practices in Schizophrenia Treatment (BeST) Center at Northeast Ohio Medical University



In Honor and Memory of

### Dr. Frederick J. Frese, III

Beloved colleague, co-author, mentor and friend

### The BeST Kind of Help:

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### The BeST Kind of Help: Tools and Tips for Schizophrenia Recovery

### **Message to Readers**

Dear Friend:

Do you or someone you love have schizophrenia?

### You are not alone.

### We care. We can help.

We are individuals affected by schizophrenia and other mental illnesses and we are family members and friends of those affected by schizophrenia. Like you, we have had good days and bad days. *The BeST Kind of Help* includes effective, easy-to-use tools and tips for schizophrenia recovery. They have helped us and our peers to recover and to stay well.

We developed *The BeST Kind of Help: Tools and Tips for Schizophrenia Recovery* through our own experiences and the experiences of others. We thank the members of Choices Community Social Center in Akron, Ohio, Summit County Peer Support, Dr. Frese's Tuesday afternoon recovery group, NAMI Greater Cleveland Peer-to-Peer class and the Ohio Center for Training, Advocacy and Support's Northeast Ohio Speakers Bureau for sharing their recovery tips and tools with us.

Our hope is that you will select two or three tips and tools that you can use often and identify others that you can use when you need them. Please consider this a "living document." Different tools and tips may be helpful at different times. Whichever tips and tools you choose, we hope that they will always be the BeST Kind of Help.

### Best Practices in Schizophrenia Treatment (BeST) Center Outreach Advisory Group

Karen Curlis, LSW Frederick J. Frese III, Ph.D. Lisa Marie Griffin Ron Rett Linda Robinson

### BeST Kind of Help One:

Learn the truth about schizophrenia

A lot of what you see or hear about schizophrenia is not true.

You may hear: The truth:	People with schizophrenia are dangerous. Most people with mental illness are not dangerous, and most people who are dangerous are not mentally ill.	
You may hear: The truth:	People with schizophrenia have split personalities. People with schizophrenia do not have split personalities.	
You may hear: The truth:	People with schizophrenia never get better. With the right treatment, people with schizophrenia can and do improve their lives. Many people with mental illnesses enrich our lives.	
You may hear: The truth:	Schizophrenia is a result of bad parenting or weak character. Schizophrenia is no one's fault. No one causes it. No one is to blame for it.	

### BeST Kind of Help Two: Learn as much as you can about schizophrenia

Schizophrenia is a serious mental illness. It affects how a person thinks, feels, behaves and views the world. It can also affect a person's ability to know the difference between what is real and what is not. Although there is no cure for schizophrenia, there are many treatments that can help individuals with schizophrenia lead fulfilling and productive lives.

### Signs and symptoms of schizophrenia:

- · Seeing or hearing things that others do not see or hear
- Having paranoid or unusual thoughts
- · Not being able to stay on task or focus
- Serious problems at work or school
- · Big changes in mood or behavior
- · Having trouble making plans
- Forgetting things
- · Problems with classmates, friends, co-workers, family members
- Lack of energy
- · Lack of interest in things
- · Decline in appearance
- · Not expressing any feelings

#### Some facts about schizophrenia:

- With treatment, people with schizophrenia can and do improve their lives
- · Schizophrenia affects about one percent of all Americans
- Average age of onset: for males, late teens to early 20s; females, mid-20s to early 30s
- Three out of every 100 people will hear voices or experience a disconnect with reality at some point. Not all will develop schizophrenia
- Half of the people with schizophrenia also have problems with alcohol or drugs
- Many people with schizophrenia do not know they have a mental illness
- · Many people with schizophrenia wait months or years before they seek help
- Recovery varies from person to person. Some people need more time to respond to treatment and return to responsibilities



#### About schizoaffective disorders

Some individuals have a schizoaffective disorder, which is related to schizophrenia. Individuals with schizoaffective disorders have many signs and symptoms of schizophrenia, but they also have problems with moods, such as depression or mania.

To learn more, follow

**J**@BeSTNEOMED **f** bestschizophreniapractices



### BeST Kind of Help Three: Take the optimistic view

As Dr. Fred Frese who was diagnosed with schizophrenia more than 40 years ago, often said, "There has never been a better time to be diagnosed with a serious mental illness. There is more hope now than ever before."

# Although there is not a cure for schizophrenia, there are reasons for people affected by schizophrenia to feel optimistic and to have hope:

- There are newer and more effective medications and other treatments, such as counseling and supported employment, that can help people with schizophrenia improve their lives.
- There are many things that people with schizophrenia can do to help themselves get better and stay well.
- There are many things that family members and friends can do to help and support their loved ones with schizophrenia.
- Only a small number of people with schizophrenia need residential care.

# BeST Kind of Help Four: Seek or stay in treatment, or encourage your loved one to do so

Many people with schizophrenia do not know that they have a mental illness, and they often wait a long time before they see a doctor, get a diagnosis and begin treatment. Family members and friends may have to encourage and help their loved one to seek professional help for schizophrenia.

#### To learn where to get mental health treatment in Ohio, visit

mha.ohio.gov

or call

### 1.877.275.6364

#### FIRST Coordinated Specialty Care for FIrst Episode Psychosis

Research shows that the early identification and treatment of psychotic illness can lead to a faster, more complete recovery. The Best Practices in Schizophrenia Treatment (BeST) Center works with mental health agencies and local mental health boards to offer FIRST programs, which are treatment programs that are specially designed to help people who have had a first episode of schizophrenia.

#### To find FIRST programs, please visit:

www.neomed.edu/bestcenter

or call

330.325.6695

### BeST Kind of Help Five: Develop coping strategies

Just like stress makes other conditions worse, stress makes schizophrenia worse. It helps to find healthy ways to cope with stress. Many people with schizophrenia find that their illness symptoms get worse when they are involved with too many things at the same time, have too much noise or too many things to look at.

Some signs of stress:

*Physical signs:* heart pounding, butterflies in stomach, nausea, headache, gritting teeth, sweating

*Mental signs:* racing thoughts, muddy thoughts, fear, focusing too much on upsetting thoughts or memories, worry, tiredness, not being able to sleep, trouble concentrating, irritability, anger, thinking people are out to get you (paranoia)

**Behavioral signs:** pacing, lashing out at others, using drugs or alcohol, not following through with things, crying for no reason, mania, hiding or withdrawing

It is important to recognize that you are getting stressed out and to find ways to relax when this is happening. Some things that work for us:

- Going to a quiet place, turning off the lights, lying down, taking deep breaths, closing eyes, placing a damp cloth on forehead
- · Listening to soft music without words or a relaxation tape
- Having a cup of herbal tea or a healthy snack
- Taking a nap or going to bed
- · Sticking to a routine; cutting down on activities
- Calling a trusted friend



There are lots of other strategies to help cope with too much stress. Try out a couple listed on the card above. Pick two or three "go to" coping strategies that work for you and practice using them when you feel stressed.



### BeST Kind of Help Six: Connect with others

People living with mental illnesses and their loved ones find it helps to connect with others who have had similar experiences. Several organizations facilitate connecting with others.

#### National Alliance on Mental Illness (NAMI)

NAMI affiliates and volunteer leaders work in local communities to raise awareness and provide free education, advocacy and support programs for people affected by mental illnesses and their families and significant others. To find the NAMI affiliate closest to you, visit **nami.org** 

#### Schizophrenia Alliance

Schizophrenia Alliance offers support groups and weekly conference calls for persons affected by schizophrenia. To learn more, visit **sardaa.org**.

#### **Certified Peer Recovery Supporters**

Peer Recovery Supporters are individuals with lived experience with mental illness who have also completed formal training as mental health peer specialists. To learn more about becoming a Certified Peer Recovery Supporter, visit **mha.ohio.gov**.

#### **Consumer-Operated Services**

Consumer-operated services offer hope, recovery, empowerment and community. To find consumer-operated services in Ohio, please visit **mha.ohio.gov/Supports/ Consumer-Operated-Services**.

#### Vet to Vet

Vet to Vet is a consumer/provider partnership program that utilizes veterans in recovery in a peer educator capacity to help other veterans through reading and discussing information about their psychiatric condition and the mental health system. To learn more, call **203.623.0731** or visit **vet2vetusa.org** 

### **BeST Kind of Help Seven:** Prepare for a mental health emergency

It is wise to be prepared for a mental health emergency.

#### Ask for help

Do not try and handle a mental health emergency by yourself. Write down the number to call for mental health emergencies in your community:

Or

Call 9-1-1 and ask if there is a CIT (Crisis Intervention Team) officer to help. CIT officers are specially trained to help with mental health emergencies, and they will assist anyone who is having a crisis to get the help they need.

If you or someone you know is in crisis, contact the **National Suicide Prevention Lifeline** at **1.800.273.8255** or visit **suicidepreventionlifeline.org** or text **4HOPE** to **741 741**, Crisis Text Line.

#### Have important information ready

Psychiatric Advance Directives are legal documents that may be used to provide specific instructions or preferences about your future mental health treatment if you have a relapse and you are not able to give consent to treatment. To learn more visit **nrc-pad.org** 

Please complete the enclosed emergency information card and carry it with you.



### BeST Kind of Help Eight: Plan for staying well

People with mental illnesses sometimes have relapses – or times when their illness becomes hard to manage again. Some reasons for relapses:

- Stress
- · Alcohol or drug use
- Change in medication, including stopping medication because people believe they no longer need it
- Physical illness
- Fatigue
- Reminders of sad or upsetting events: the birthday of someone who has passed away, the date that something bad happened
- · Sometimes for no apparent reason

It helps to have a plan for staying well. A plan for staying well includes:

- Doing things that make life less stressful
- · Knowing the warning signs of relapse
- · Taking action when a relapse might be coming on
- · Listening to trusted friends and family members who express concern

#### Things that help reduce stress

- Taking a course such as:
  - Wellness Recovery Action Plan (WRAP): Contact The Copeland Center for Wellness & Recovery at http://copelandcenter.com.
  - NAMI Peer-to-Peer: Check www.nami.org to find a NAMI near you and contact your local NAMI to see if it offers a Peer-to-Peer course.
- Having a daily routine, including planning to do things when your energy and concentration are at their peak
- · Relaxing every day
- · Getting enough sleep

#### Warning signs that may mean a relapse:

- Wanting to disappear
- Feeling numb
- Not caring about getting better
- Talking too much or not at all
- Not listening, concentrating or following what others are saying
- Feeling angry: "Anger is danger without the D"
- Using alcohol or drugs

- Having trouble solving problems or making decisions
- · Hearing voices
- Feeling paranoid
- Blushing, sweating, "butterflies in your stomach," tight fists, fast heart rate, fast breathing
- Worrying
- · Withdrawing

#### Actions to prevent relapse:

- About half of the people in the groups we talked with wanted to be alone when they felt a relapse coming on, and about half said that they wanted to be with caring relatives, friends or their pets. It is important to think about which works for you
- Take time to figure things out
- Make a list of things that are going well in your life

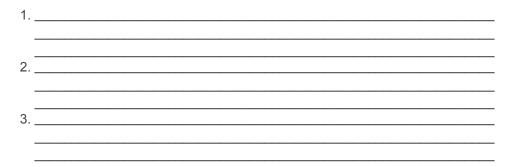
- Get involved in activities that you enjoy
- Get 6-8 hours sleep per night
- Stick to a routine
- Take a walk or go for a drive, especially if it is nice outside
- Exercise (be sure to check with your doctor first.)

Consider these questions as you begin to develop a plan to stay well.

### List three things you can do to make your life less stressful.

1.	
-	
2.	
-	
3.	
-	

### List three warning signs that you or your loved one might be having a relapse.



# List three things that you can do if you think you or your loved one is about to have a relapse.

1.\_\_\_\_\_ 2.\_\_\_\_\_ 3.\_\_\_\_\_

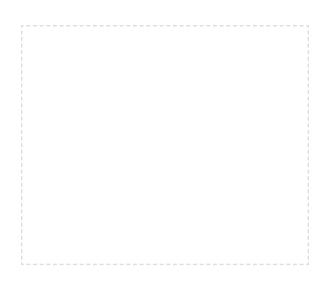
### **BeST Kind of Help Nine:** Follow guidelines for family members and friends

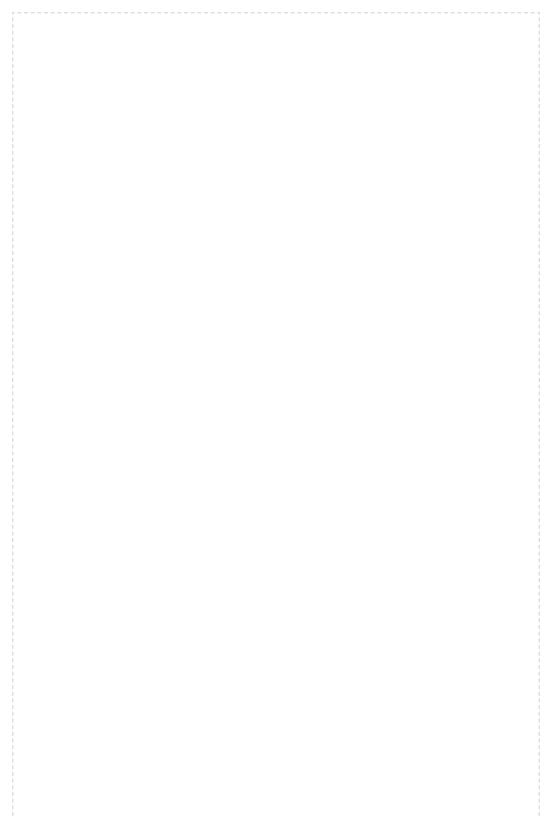
Please post the guidelines on page 15 where you can see them every day.

### BeST Kind of Help Ten: Show your support

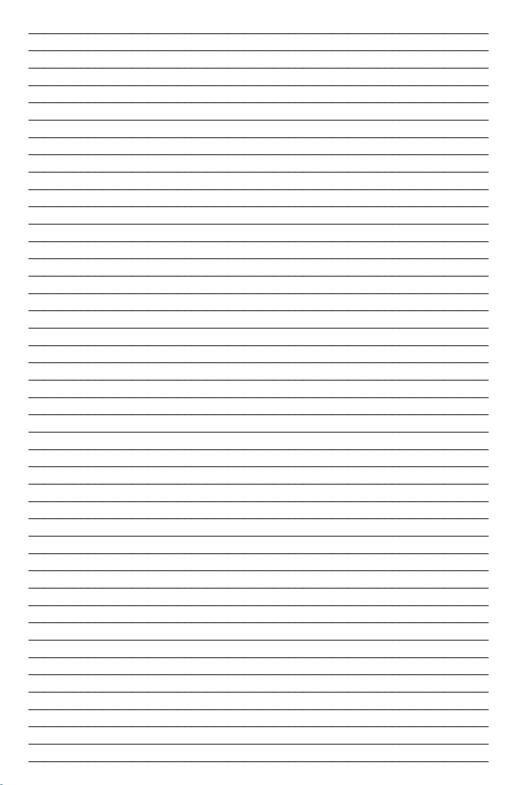
### Ways you can show your support for people affected by schizophrenia:

- By not using terms such as insane, crazy/crazed, nuts or psycho.
- By calling people who have schizophrenia "people who are affected by schizophrenia" – and not calling them schizophrenics. They are people first. Their illness is only one part of who they are.
- By not using mental health terms when talking about non-health issues. For example, do not say that a baseball team that wins one game and loses the next is schizophrenic.





Notes:







The mission of the Best Practices in Schizophrenia Treatment (BeST) Center at Northeast Ohio Medical University is to promote recovery and improve the lives of as many people with schizophrenia as possible by accelerating the adoption of evidence-based and promising practices.

> www.neomed.edu/bestcenter 330.325.6695 bestcenter@neomed.edu Promoting Innovation. Restoring Lives. @BeSTNEOMED f bestschizophreniapractices

