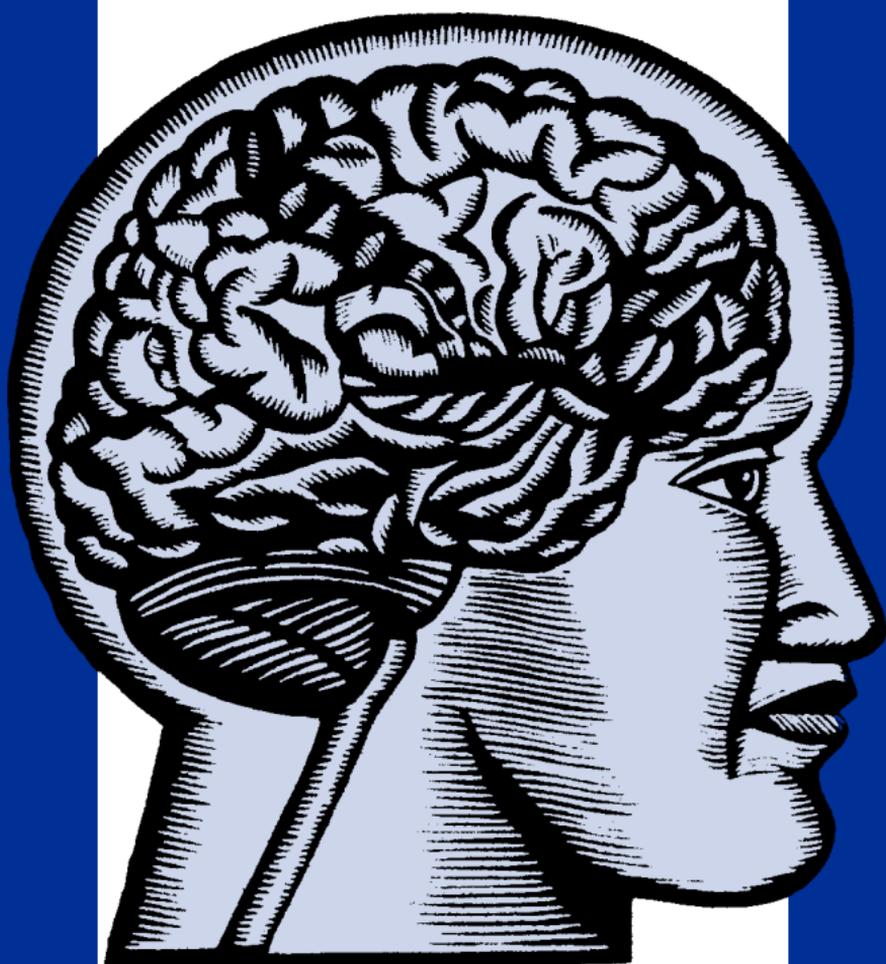


UNDERSTANDING SCHIZOPHRENIA:

WHAT YOU NEED TO KNOW
ABOUT THIS MEDICAL ILLNESS



 **NAMI**
The Nation's Voice on Mental Illness

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INTRODUCTION

Schizophrenia is a serious medical illness that affects about two million Americans today. Although it is often feared and misunderstood, schizophrenia is actually a highly treatable disorder of the brain. New discoveries and treatments are continually improving the outlook for people with this disorder. With the new medications and services, people with schizophrenia less often need hospitalization, and they often recover to lead independent and productive lives in their communities.

Left untreated, however, schizophrenia can destroy the lives of individuals, families, and communities. Because the disorder causes unusual, inappropriate, and sometimes dangerous behavior in people who do not get treatment, they are often shunned and unnecessarily stigmatized. They may also face poverty and homelessness, or even commit suicide.

Reading this booklet is an important first step to answering your questions and getting proper medical care for schizophrenia. As difficult as schizophrenia is, help is available. Doctors know more about the disorder today than ever before, and frequently people with schizophrenia can get better and lead full, meaningful lives. This booklet will explain the symptoms and causes of and the treatments for schizophrenia and tell you where you and your family can turn for the medical care and support needed to manage this chronic illness.

WHAT IS SCHIZOPHRENIA?

Schizophrenia is a brain disorder that interferes with a person's ability to think clearly, manage emotions, make decisions, and relate to others. Many people with schizophrenia have hallucinations and delusions, meaning they hear and see things that aren't there and believe things that are not real or true.

Research has linked schizophrenia to changes in brain chemistry and structure, and some of these changes may be present very early in life. Like cancer or diabetes, schizophrenia is a complex, chronic medical illness affecting different people in different ways.

Schizophrenia is not caused by bad parenting or personal weakness. A person with schizophrenia does *not* have a "split personality," and almost all people with schizophrenia are *not* dangerous when they are in treatment—although their behavior can be quite unpredictable or unusual.

WHAT ARE THE SYMPTOMS?

No single symptom positively identifies schizophrenia. All of the symptoms of this disorder can also be found in other brain disorders. In addition, a person's symptoms may change over time. There is no lab test for schizophrenia. However, when a doctor sees the symptoms and watches the course of the illness over six months or more, he or she can almost always diagnose schizophrenia correctly.

Altered senses. People with schizophrenia have trouble making sense of everyday signs, sounds, and feelings. They may see the world around them as distracting or frightening and may become extra-sensitive to colors, shapes, and background noises. They may even have trouble telling the difference between themselves and others or between themselves and objects around them.

Hallucinations, delusions, and confused thinking. Commonly, schizophrenia causes *hallucinations*, which means hearing voices or seeing things that don't exist. Or, people with the disorder may have *delusions*, which means that they believe ideas that are obviously false, such as that they are God or that they can control other people's minds. Schizophrenia also often causes people to experience interrupted or confused thinking and to talk without making sense.

Altered or blunted emotions. The disorder can cause people to express feelings inappropriately. They may laugh at the death of a loved one or become angry when a favorite team wins a game. Sometimes people with schizophrenia feel or express no feelings at all. Understandably, it's hard for people with such symptoms to relate normally to others, and they generally have intense periods of withdrawal and extreme isolation.

Other behavioral changes. Schizophrenia can cause people to move more slowly, make rhythmic gestures over and over again, or move in ritualistic ways, such as walking in circles. Some people with schizophrenia have almost no motivation and have trouble finishing tasks. In severe cases, the illness can cause people to stop speaking completely or to stop moving and hold a fixed position for long periods of time.

To correctly diagnose schizophrenia, a medical doctor must rule out many other biological illnesses. To have schizophrenia, a person must have psychotic or "loss of reality" symptoms for at least six months and show that he or she is

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BUT IT'S NOT,
BECAUSE YOU'RE
NOT ASLEEP.
AND BECAUSE
YOU'RE NOT ASLEEP,
YOU CAN'T WAKE
UP . . ."

having greater and greater problems acting and doing things normally.

WHO GETS SCHIZOPHRENIA?

People can get schizophrenia at any age, but three-quarters of those with the disorder develop it between the ages of 16 and 25. It affects slightly more men than women. Children can also have schizophrenia. New cases are quite rare after age 40.

Although the disorder runs in families, the chance of becoming ill with schizophrenia is very small for most people. If no one in your family has ever had the disease, the chances are 99 out of 100 that you won't either. If one of your parents, a brother, or a sister has schizophrenia, there's still about a 90-percent chance that you will never develop the disorder. If both your parents have schizophrenia, there is more than a 60-percent chance that you will never have it. And, if you have an identical twin with schizophrenia, there is a 70-percent chance that you will not become ill.

WHAT CAUSES SCHIZOPHRENIA?

Scientists still don't know exactly what causes schizophrenia, but they do know that the brains of people with schizophrenia are different, as a group, from the brains of those who don't have the disorder. Research suggests that schizophrenia has something to do with problems with brain chemistry and brain structure. It is as much an organic brain disease as is multiple sclerosis, Parkinson's disease, or Alzheimer's disease.

Increasingly, it seems that schizophrenia—like many other medical illnesses such as cancer, heart disease, and diabetes—is caused by a combination of problems, some inherited and others occurring during a person's

development. For example, some scientists think that schizophrenia may be triggered by a viral infection affecting the brain very early in life or by mild brain damage from complications during birth.

HOW IS SCHIZOPHRENIA TREATED?

Medication. Schizophrenia can usually be successfully treated. As with diabetes, a cure for schizophrenia has not yet been found, but most people's symptoms can be controlled with medication. The primary medications for schizophrenia, called *antipsychotics* or *neuroleptics*, help relieve the hallucinations, delusions, and thinking problems people have with the disorder. These drugs seem to work by correcting an imbalance in the chemicals that help brain cells communicate with each other.

For years, all antipsychotic medications worked pretty much the same for relieving symptoms. They were mostly different in the side effects they produced. These earlier medications are now called conventional antipsychotics, and they include chlorpromazine (Thorazine), fluphenazine (Prolixin), haloperidol (Haldol), thiothixene (Navane), trifluoperazine (Stelazine), perphenazine (Trilafon), and thioridazine (Mellaril).

Because of research, there is now a new generation of antipsychotic drugs called "atypical" antipsychotics. Compared with conventional antipsychotics, these medications appear to be equally effective for helping with hallucinations and delusions—called *positive symptoms*—but may be better than the conventional drugs for helping the *negative symptoms* of the disease, such as withdrawal, problems in thinking, and a lack of interest and energy.

The new drugs also have different side effects. Clozapine (Clozaril) was the first atypical antipsychotic in the United States, and it is now the only one available as a generic (non-brand-name) as well as a brand-name drug. Although clozapine seems to be a very effective medication, particularly for people who have not responded well to other drugs, it requires blood monitoring every one to two weeks to check for a very rare but serious problem in which too few white blood cells are produced. The other atypical drugs now available in the United States appear to work as well as clozapine, but without the need for blood monitoring. These drugs include risperidone (Risperdal), olanzapine (Zyprexa), and quetiapine (Seroquel). All the atypical antipsychotics seem to have a low risk of causing *tardive dyskinesia*, a movement disorder that is the most troubling problem with conventional antipsychotic drugs. (See definition on page 8.)

“THE REFLECTION
IN THE STORE
WINDOW—IT’S ME,
ISN’T IT? I KNOW
IT IS, BUT IT’S HARD
TO TELL. GLASSY
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PUZZLE OF MY
BODY, FACE,
AND CLOTHES,
WITH PIECES
DISAPPEARING
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MOVE . . . YET I
SENSE THAT
IT’S ME. I JUST
KNOW.”

Because of these differences, the atypical antipsychotics are the ones many people and their doctors prefer. However, for people already taking a conventional antipsychotic drug that is working well, a change may not be a good idea. Also, only conventional antipsychotics can now be injected to treat during emergencies, and only these older drugs are available in what is called “depot” forms, which can be injected

every one to four weeks to help people who cannot remember to take their medication.

Ongoing efforts to develop more effective drugs with fewer side effects promise even more treatment options in the future for people with schizophrenia.

Psychosocial rehabilitation. While psychotherapy by itself does not work well to treat the symptoms of schizophrenia, individual and group counseling and education about the illness can provide important information, support, skills-building, and friendship for people with the disorder and their families. Research shows that people who attend structured psychosocial rehabilitation programs and continue with their medical treatment manage their illness best.

Hospitalization. Most people who become ill with schizophrenia need to be hospitalized for a period of time when their symptoms are particularly bad. Once they are on a course of medication that works for them, they usually can get the support and treatment they need from day programs, rehabilitation centers, and other outpatient services. When people become very sick again, or relapse, and need to be rehospitalized, it is often because they have stopped taking their medications.

**WHAT ARE THE
POSSIBLE SIDE
EFFECTS OF
DRUGS USED
TO TREAT
SCHIZOPHRENIA?**

Perhaps the most important message about side effects is: *discuss them frankly with your doctor.* All treatments have side effects, different drugs have different side effects, and people differ in whether or not they are bothered by the side effects or experience them at all. Side effects can often be treated by changing the dose of the medication, by treating the side effect itself (perhaps

with another medication added to treatment), or by switching to a different medication with different side effects.

Common side effects of drugs used to treat schizophrenia include dry mouth, constipation, blurred vision, and drowsiness. Some people have less sexual desire, menstrual changes, or significant weight gain. Other side effects relate to muscles and movement, including restlessness, stiffness, tremors, or probably the most unpleasant, serious side effect of antipsychotic drugs, a condition called *tardive dyskinesia*. Tardive dyskinesia consists of facial movements that can't be controlled and sometimes includes jerking or twisting movements of other parts of the body. This condition is hard to treat and it happens in some people who take antipsychotic drugs, usually after several years of treatment. Tardive dyskinesia affects perhaps 15 percent to 20 percent of people who take conventional antipsychotic drugs. Using the newer, atypical antipsychotics makes it much less likely that a consumer will develop tardive dyskinesia.

**HOW SUCCESSFUL
ARE TREATMENTS
FOR A PERSON
WITH
SCHIZOPHRENIA?**

Most people with schizophrenia can get better with the treatments doctors now use, and the future is promising. Today's exciting new brain research and the new drugs we expect in the future offer hope that more people will be helped.

Medication appears to make the long-term outlook good for people with schizophrenia. Studies now show that after 10 years of treatment, one-fourth of the people with schizophrenia studied recovered completely, one-fourth improved a great deal, and one-fourth

improved, but not so much. Fifteen percent did not get better, and 10 percent died, usually by suicide or accident. Research is showing that if more people with schizophrenia use the newer antipsychotic agents, the overall results of treatment may improve.

**WHAT HELP
DOES A PERSON
WITH
SCHIZOPHRENIA
NEED?**

Above all, people with schizophrenia need a correct diagnosis and early treatment of their illness. But they also need understanding, compassion, and respect. Like anyone else with a serious, ongoing illness, a person with schizophrenia needs help with the fear and isolation caused by his or her disorder as well as the stigma surrounding it.

Because of the problems in thinking and judgment that may be a part of schizophrenia, people with this illness may also need help understanding that they need treatment, staying in treatment, and knowing the signs that they are getting sick again and need to quickly see a doctor and follow his or her treatment suggestions. Doing this can prevent re-hospitalization.

Because the illness makes it so hard to do even everyday things they did before, some who have this disorder need help with their physical care—from staying clean and eating well to following medical treatment. Although new and better treatments allow many people to return to a more normal life, many suffering from schizophrenia will need help over the long term with their basic needs, such as money, housing, food, and clothing.

**HOW CAN
FAMILY AND
FRIENDS HELP?**

Finding good treatment and paying for it. If you think that perhaps someone you

know and love has schizophrenia, the most important thing you can do is to help that person find medical treatment that works and then encourage him or her to stay with it. To find a good psychiatrist, you may want to ask your own family doctor to suggest one or contact the psychiatry department of a university medical school. You may also call NAMI's HelpLine at 1-800-950-NAMI (6264) to talk with others who have a family member with schizophrenia or to find out how to contact a local NAMI affiliate for help and support.

Paying for treatment is hard for many people with schizophrenia and their families. Health insurance coverage for psychiatric illnesses, when available, usually includes high deductibles (money you have to spend before your insurance begins to pay) and co-payments (the part of the medical bill you must pay). There also may be fewer paid-for visits and other restrictions that make coverage for mental illnesses not as good as coverage for other medical disorders. For some people, coverage has improved because of the passage of *parity* (equality) laws in many states. But even in states with laws stating that insurance coverage for mental illnesses must be the same as for other illnesses, consumers and families may find other reasons they cannot get effective treatment. When this happens, family members have to speak out, insist on good treatment, and fight for their loved one's rights.

**"MY EMOTIONS
INWARDLY WERE
AT A FEVER'S
PITCH AND IT
SEEMED TO ME
THAT I WAS ONLY
FEELING, NOT
THINKING."**

Public programs such as Medicaid and Medicare help some people pay for treatment. Also, programs such as Supplemental Security Income (SSI) and Social Security Disability Insurance

(SSDI) help some families with low incomes. Social workers or case managers may be able to help you find out if you can get such help and get you through the red tape, but you may have to contact your local Social Security or social services office yourself to find out what benefits you can get and how to apply for them. Then you may need to help your ill loved one apply for these benefits. People who depend on SSI or SSDI as their only source of income generally can get treatment for a reduced fee if they go to their local community mental health center.

Handling symptoms. When you face the symptoms of schizophrenia in a loved one, you can help most if you have learned everything you can about the disorder. Try your best to understand what the person is going through and why the illness causes upsetting or difficult behavior. For example, it's important to know that when people are hallucinating or having delusions, the voices they hear and what they see are very real to them. Do not argue, act frightened, or make fun of the situation. It's important to stay calm, state that you are trying to understand how the person is feeling, and do what you can to help him or her feel safe or more in control.

Managing crises. In some cases, behavior caused by schizophrenia can be bizarre or even dangerous. If you must deal with bizarre behavior, do your best to stay calm. Do not criticize. Be clear and direct in whatever you say and don't talk too much. Chances are the actions, while strange, are not threatening.

If behavior becomes violent or dangerous, you can help by staying calm and being clear about the limits of acceptable behavior. Do not make sudden or threatening moves. State quietly that you care and want to help. In some areas, there are specially trained teams

either at the community mental health center or occasionally in the police force that may be able to help you and your loved one. If you cannot stop the person from doing something dangerous, your last resort is to call the police. Your safety and the safety of the ill person must always come first.

Committing the ill person to the hospital. Because people with schizophrenia often don't understand or know that they are ill, getting them to accept treatment can be difficult. If you can't get an ill person who is getting worse to agree to get psychiatric treatment, you may be able to commit the person to treatment without his or her consent (*involuntary commitment*). Because each state has its own laws for psychiatric commitment, the laws are different in each one. Laws that allow involuntary commitment are meant to protect people who are acutely ill from hurting themselves or others and to get them the treatment they need. If someone in your family needs treatment and will not go to the hospital, you must find out what the laws on involuntary commitment are in your state. You can find out by calling or visiting the admissions office of the nearest state psychiatric hospital. The staff are usually experts in this area. Or you can call a crisis hotline. If you still can't find answers, call your state department of mental health, a local psychiatrist, your local or state NAMI, or the police.

HOW CAN FAMILIES COPE WITH SCHIZOPHRENIA?

A diagnosis of schizophrenia can mean hardships not only for the ill person, but also for his or her family. Because so many people are afraid and uninformed about the disorder, many families try to hide it from others and deal with it on their own.

If someone in your family has schizophrenia, you, too, need understanding, love, and support from others. You may need to learn and accept that no one causes schizophrenia, just as no one causes diabetes, cancer, or heart disease. You are not to blame—and you are not alone.

To deal with schizophrenia, one of the most important steps you can take is to join a family and/or consumer support group. More than 1,200 such groups under the name of NAMI are now active in local communities in all 50 states. Members of these groups share information and ideas about everything from coping with symptoms to finding financial, medical, and other resources.

Families who deal most successfully with a relative who has schizophrenia are those that come to accept the illness and its difficulties, are realistic about what they expect of the ill person and of themselves, and even keep a sense of humor. Developing and holding onto such attitudes is an ongoing process for most people, but it can happen more easily and quickly with the understanding support of others.

Schizophrenia causes many problems, but it does not have to destroy you or your family. To deal with it best, it's very important for you to take care of yourself and to continue doing things you enjoy. You cannot let the illness take over your life. Scientists believe that new discoveries and new treatments will bring new hope to more people with schizophrenia in the future. In the meantime, try to help the ill person live the best life he or she can today, and do the same for yourself.

WHAT IS NAMI?

NAMI is a national grassroots, family and consumer, self-help, support, and advocacy

organization dedicated to improving the lives of people with serious mental illnesses and their families. It has more than 1,200 affiliates. To learn more about your local group, call your state's NAMI office or write to NAMI, Colonial Place Three, 2107 Wilson Blvd., Suite 300, Arlington, VA 22201-3042. You can also call the NAMI HelpLine at 1-800-950-NAMI (6264) to find out how to reach a local NAMI, to get information about schizophrenia, or to talk with someone who is a family member or a consumer with the disorder.

SERVICES

Through affiliate groups that bring families and consumers together at the state and local levels, NAMI provides a wide range of services to people across the country. Two of the services you may want to use first include:

The NAMI HelpLine (1-800-950-NAMI [6264]). NAMI's national, toll-free HelpLine number connects callers with volunteers who answer questions about severe mental illnesses and will mail information about disorders, treatments, local affiliate support groups, and other local services.

Self-help support groups. Regularly held NAMI meetings for people with severe mental illnesses and their families provide a forum for people to share concerns, learn more about brain disorders, get emotional support, and find answers to questions about health insurance, income supports, medical treatment, housing, employment, and community resources.

BOOKS ABOUT SCHIZOPHRENIA

(Call or visit your local bookstore to get or order the following books.)

Breakthroughs in Antipsychotic Medications: A Guide for Consumers,

Families, and Clinicians by Peter J. Weiden, M.D., Patricia L. Scheifler, M.S.W., Ronald J. Diamond, M.D., and Ruth Ross, M.A. W.W. Norton, 1999.

Conquering Schizophrenia: A Father, His Son, and a Medical Breakthrough by Peter Wyden. Knopf, 1998.

Coping with Schizophrenia: A Guide for Families by Kim T. Mueser, Ph.D., and Susan Gingerich, M.S.W. New Harbinger, 1994.

My Mother's Keeper: A Daughter's Memoir of Growing Up in the Shadow of Schizophrenia by Tara Elgin Holley with Joe Holley. William Morrow, 1997.

Surviving Schizophrenia: A Manual for Families, Consumers and Providers by E. Fuller Torrey, M.D. Harper Perennial, 1995.

FROM NAMI

(These materials are available by calling the NAMI HelpLine, 1-800-950-NAMI [6264].

Other information can be found by visiting our Web site, www.nami.org.)

Schizophrenia & Genetic Risks: A Guide to Genetic Counseling for Consumers, Their Families, and Mental Health Workers, a brochure written by Irving I. Gottesman, Ph.D., Hon. F.R.C. Psych (London), and Steven O. Moldin, Ph.D., 1999.

Tardive Dyskinesia, a NAMI Medical Information Series brochure, 1998.

NAMI fact sheets on the antipsychotic medications Clozapine (1998), Risperdal (1995), Seroquel (1997), and Zyprexa (1996).

Join NAMI Today!

As a member of NAMI, you will join forces with parents, spouses, siblings, friends, and people with mental illnesses. You can become a NAMI member today by filling out the form and sending it back to us. We need your voice along with our 210,000 members to advocate for better treatment of these no-fault brain disorders and a better quality of life for people who have them. Become a member today to start making a difference!

Benefits of membership (for all membership categories):

- Subscription to NAMI's bimonthly newsletter, the *Advocate*, which features cutting-edge articles about the latest research, treatments, and medications for mental illnesses; the status of major policy and legislation at the federal, state, and local levels; and provocative editorials and columns.
- Availability of books, brochures, and fact sheets with the most current information on brain disorders, medications, and related issues.
- A discount on the registration fee for the annual NAMI convention.
- Literature from your state NAMI with specific information about services, grassroots advocacy, and educational activities in your area.
- The availability of NAMI's toll-free HelpLine, 1-800-950-NAMI (6264), which responds with science-based information about mental illnesses and how to best live with them.

NAMI MEMBERSHIP OPTIONS

Choose one of the following membership categories:

Individual/Family Membership \$25 annual dues.

Receive all the benefits of membership.

Professional Membership \$40 annual dues.

Mental illness service providers receive all the benefits of membership as well as a professional membership certificate and 50 NAMI brochures with a display stand.

Open-door Membership \$3 annual dues.

Individuals/families/consumers with limited means are invited to join NAMI at a reduced annual membership rate (\$3 or any amount you wish to contribute).

Please renew my NAMI membership.

This is a gift for (name) _____

(address) _____

(city) _____ (state) _____ (zip) _____

I have also included, in the payment method noted below, a TAX-DEDUCTIBLE GIFT for NAMI to continue its important work.

Name _____

Organization _____

Address _____

Suite/Apt. # _____

City _____ State _____

Zip _____ Day Phone () _____

Email _____

Payment Method (check box)

Check Money Order Master Card

Discover American Express Visa

Card # _____

Exp. Date _____

Signature _____

Please make all checks and money orders payable to NAMI.

Return this application in an envelope to:

NAMI
Colonial Place Three
2107 Wilson Blvd., Suite 300
Arlington, VA 22201-3042

Or JOIN BY PHONE by calling our toll-free number with your credit card information. Call today! 1-800-999-NAMI (6264)

Your name and a portion of your membership dues will be shared with your state's NAMI organization to provide local support for our efforts.

Please detach, complete and mail this application.





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