

accept it and then moving beyond it.

This includes learning coping mechanisms, believing in themselves as individuals by learning their strengths as well as their limitations, and coming to realize that they do have the capacity to find purpose and enjoyment in their lives in spite of their illness. **RECOVERY IS POSSIBLE!**

## How to Get Help

No insurance? Call the NAMI Southern Arizona office to help guide you to access mental health services.

### If you have Tardive Dyskinesia

- ◆ Seek medical care through a psychiatrist and/or your primary care physician.
- ◆ Find the right combination of treatment that works for you which may include medication, therapy, support groups, etc. *\*Sometimes people must try several different treatments or combinations of treatment before they find the one that works for them.*
- ◆ Take NAMI's Peer-to-Peer course and/or join the NAMI Connection support group.
- ◆ LEARN about your illness. The more you know, the more you are able to help yourself. Start with NAMI today!

### If you are a family member with a loved one who has mental illness:

- ◆ Take care of yourself.
- ◆ Take NAMI's Family-to-Family course, join a Family & Friends Support Group and/or take NAMI Basics if you have a loved one who is a child or adolescent.

- ◆ Learn about your loved one's illness.

## NAMI Programs & Services

### ADVOCACY\*

We offer advocacy for individuals with mental illness as well as for family members. You or your loved one may ask us about patient rights, how to obtain quality mental health services, and more.

### EDUCATION

**Family to Family\***: A 12-class course for family and friends of adults with mental illness.

**Homefront**: A 6-class course for family, friends and partners of military service members and veterans with mental health conditions.

**NAMI Basics**: A 6-class course for parents and caregivers of children or adolescents with a mental illness.

**Peer to Peer\***: A 10-class course for people with mental illness focusing on recovery.

**In Our Own Voice\***: A presentation given by individuals with mental illness providing their testimonies.

**Ending the Silence**: An early intervention program that engages students in mental health education and discussion.

**Parents and Teachers as Allies**: An in-service education program for school professionals, parents, and agencies working with children and adolescents.

### SUPPORT

**Family and Friends Support groups\***

*\*Program or Service Available in Spanish*

# TARDIVE DYSKINESIA

**SHOW YOU CARE.  
WEAR A SILVER RIBBON.**



- Help break down the barriers to treatment and support.
- Help reduce stigma —talk about it!



**FIND HELP.  
FIND HOPE.**

Mental illness affects 1 in 5 people. We provide resources and support to all those affected by mental illness.

**NAMI SOUTHERN ARIZONA DEPENDS ON YOU.  
THERE ARE MANY WAYS TO HELP.  
BECOME A MEMBER, VOLUNTEER OR DONATE.**

NAMI Southern Arizona  
6122 E. 22nd St.  
Tucson, AZ 85711  
520-622-5582  
NAMIisa@NAMIisa.org

**COMMUNITY-WIDE CRISIS LINE:**  
520-622-6000 or 1-866-495-6735

NAMIisa.org



Educational information and local support provided by:



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## What is tardive dyskinesia?

Tardive dyskinesia (TD) is one of the most disturbing potential side effects of antipsychotic medications. Tardive (late) Dyskinesia (bad movement) is a movement disorder that occurs over months, years and even decades. TD is a principle concern of first generation antipsychotic medication but has also been reported in second generation antipsychotic medication and needs to be monitored for all people who take these medications.

TD is one of a group of side effects called “extrapyramidal symptoms” that includes akathisia (restlessness), dystonia (sudden and painful muscle stiffness) and Parkinsonism (tremors and slowing down of all body muscles). TD is perhaps the most severe of these side effects and does not occur until after many months or years of taking antipsychotic drugs. TD is primarily characterized by random movements of different muscles within the body and can occur in the tongue, lips or jaw (e.g., facial grimacing). TD may also consist of purposeless movements of arms, legs, fingers and toes. In some severe cases, TD can include swaying movements of the trunk or hips or affect the muscles associated with breathing. TD can be quite embarrassing and—depending on its severity—can be disabling as well.

Because there are a number of other medical and neurological conditions that can cause uncontrollable or strange body movements, a long history of treatment with antipsychotics must be documented before diagnosis with TD is even considered. For example, a number of neurological and muscular conditions may

cause uncontrollable body movements including Parkinson’s disease, Huntington’s disease and strokes. Therefore, any person with the onset of uncontrollable movements should discuss these symptoms with their doctors.

## Who is at risk for developing tardive dyskinesia?

Many people with serious and chronic mental illness, such as schizophrenia, require long term treatment with antipsychotic medications. While ongoing antipsychotic treatment can be very helpful or even life-saving for many people, it comes with the risk of developing TD. Not all people exposed to long term treatment with antipsychotics will develop TD, and some people are at increased risk for developing this side effect when compared with others. Some common risk factors for developing TD are as follows:

- ◆ Longer duration of treatment with antipsychotic medications
- ◆ Exposure to high-potency first generation antipsychotics (e.g., haloperidol (Haldol), fluphenazine (Prolixin), risperidone (Risperdal]) as opposed to certain newer—“Second Generation”—antipsychotics (e.g., clozapine (Clozaril), quetiapine (Seroquel))
- ◆ Older age of the individual receiving these medications (e.g. post-menopausal females)
- ◆ Alcoholism or another substance abuse disorder
- ◆ Female gender
- ◆ African-American or Asian ethnicity

The exact neurological basis of TD is still unknown despite extensive research. All antipsychotic medications change the activity of a chemical within the brain involved in communication between neurons (a neurotransmitter called “Dopamine”). While this is useful in decreasing the symptoms of psychosis, such as delusions and hallucinations, it also changes the brain’s ability to coordinate the body’s muscular movements.

Due to a number of factors, it is very difficult to determine exactly who will develop TD or what the exact risk of developing TD might be for a person treated with antipsychotic medications.

Some scientific studies suggest that approximately 5 percent of people treated with antipsychotics will develop TD for each year of treatment. The overall risk of developing TD over the course of one’s ongoing treatment is between 30 to 50 percent.

## Are there effective treatments for tardive dyskinesia?

The most effective treatment for TD is prevention. Because usually months to years of antipsychotic treatment pass before the onset of TD, people taking medications should see their psychiatrist for regular evaluations to ensure that any signs of TD are recognized before they become severe. Most psychiatrists will use a standardized rating scale called “The Abnormal Involuntary Movement Scale”—AIMS for short—to screen for TD at least once each year. This can help to stop TD before it starts.

The majority of people who develop TD will find that it is mild and reversible and the percentage of patients who develop severe or irreversible TD is quite low. For people who are developing the signs and symptoms of TD, the most important thing to do is to talk with their psychiatrist. Decreasing the dose of one’s antipsychotic medications is often the most effective treatment. Many people will find that their symptoms improve significantly at lower doses of antipsychotics. If this is not possible or does not relieve the symptoms of TD, some psychiatrists may recommend switching from one medication to a different one. However, this can also lead to the worsening of psychotic symptoms, which further emphasizes the importance of having a long discussion with one’s psychiatrist prior to making any changes.

Unfortunately there is no medication that can cure TD. A number of different medications have been studied—including benzodiazepines (e.g., lorazepam (Ativan), clonazepam (Klonopin)), anticholinergic medications (e.g., benztropine (Cogentin)), and supplements (e.g., Vitamin E, branched chain amino acids, Gingko Biloba)—but it remains unclear whether any of them can prevent or treat TD at the current time. The antipsychotic clozapine may have some efficacy in selected cases of TD.

## Recovery

Recovery does not mean that the illness has gone into complete remission. Over time, and after what for many can be a long and difficult process, individuals can come to terms with their illness by first learning to