

DYSTONIA
MEDICATION
FACTS.....DMF...

A RESOURCE GUIDE FOR YOU



Medical Disclaimer: The enclosed information has been written to help increase your knowledge about the medications used to treat Spasmodic Torticollis. Care4Dystonia, Inc. take responsibility for adverse effects or any other related events that may occur with the use of the enclosed medications. You should clarify the use of any of the medications mentioned in this resource guide with your personal physician.

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WE HOPE YOU FIND THIS RESOURCE GUIDE HELPFUL.
WE ASK THAT YOU REREAD OUR MEDICAL DISCLAIMER.

Care4Dystonia, Inc.

Classification of Dystonia

Dystonia : A Movement Disorder
 A Neurological Disorder
 Not a Psychological or Seizure Disorder

Classification

1. Focal- blepharospasm, oromandibular, spasmodic dysphonia, cervical (ST), task-specific
2. Multifocal
3. Segmental
4. Generalized
5. Hemidystonia
6. Primary (idiopathic)
7. Secondary
8. Hereditary degenerative diseases
9. Child-hood Onset
10. Adolescent Onset
11. Adult Onset

Have you had the following tests done ? They should be considered by your movement disorder specialist.

Bone X-rays
Bone Marrow
Brain Imaging
 C.T. Scan
 MRI
 PET Scan
 FDOPA
Copper, slit lamp eye exams
CSF exam
DNA testing
EEG
VEP
EMG
Nerve Conduction Studies
Muscle biopsy
Nerve Biopsy
Video Monitoring

LEARN THE PATIENT BILL of RIGHTS...EVERY STATE has them...Access Useful Med Info...

Back to Prescription Basics...



An estimated 350,000 people carry the diagnosis of some form of dystonia in North America. Spasmodic torticollis is a focal form of dystonia specifically involving the neck (cervical) muscles. Currently there is no known cure for spasmodic torticollis. Use of oral medications, either alone or in combination with botulinum toxin injections and surgical denervation, are the mainstays for symptom relief today.

New and upcoming "torticollis therapies" including various forms of botulinum toxin, phenol and surgical options that are being evaluated in federal-funded research clinical trials at several major medical centers today.

This section of "Dystonia Med Facts " will be devoted to providing you with detailed information regarding the use of oral medications prescribed by your neurologist or movement disorder specialist.

First ,lets review prescription drug "basics". The following information are general points that apply to almost all drugs including those prescribed for spasmodic torticollis.

PHARMACY BASICS....

It is good practice to purchase all of your prescriptions from the same pharmacy. With the advent of computers, many pharmacies maintain patient profile records. These records include up-to-date listings of current prescriptions, health-insurance information, physician listings, number of remaining drug refills as well as individual allergy listings. Thus, if a newly prescribed drug has the potential to interact with a drug currently being taken, your pharmacist can quickly alert you and your physician before an adverse reaction is likely to occur.

Prior to selecting a pharmacy for filling a prescription, it is helpful to know whether a prescription can be delivered to your home. This is important when your "torticollis" "acts up" and prevents you from traveling to the pharmacy.

✓CHECK IT OUT...

Is Your Pharmacist licensed to practice PHARMACY ?

To practice Pharmacy ALL pharmacists must pass a licensing exam in the state they wish to practice in.

You should always check your prescription refill prior to leaving the pharmacy at the time of "pick-up". If the drug in the refill differs in size, color, amount, or shape from your original refill, QUESTION YOUR PHARMACIST immediately.

Anticipate emergencies and other events (bad weather, holidays, etc.) that may interfere in a prescription refill "pick-up". Keep an adequate supply of all your medications by having each prescription filled before you "run out" of your supply.

Avoid refilling prescriptions during lunch or pharmacy closing hours.

These hours can be the busiest for pharmacists. You may avoid excessive waiting by calling your pharmacist first before obtaining your refill. Some pharmacies have implemented telephone touch-tone prescription refill services that allow you to "dial in" your prescription refill from any where in the world.

STORAGE BASICS....

The term DRUG refers to any nonprescription (over-the-counter) as well as prescription drug. A drug should always be kept in its original container. The effectiveness of some drugs can be altered by exposure to light, cold, moisture, and heat. The brown bottles that are used today by pharmacists are light-resistant. If color changes or an odor develops, return the drug in its original container to your pharmacy as soon as possible. Thus, it is also important to never remove the original label on a drug container. The "altered" drug may need to be evaluated by the drug or pharmaceutical manufacturer. In addition, the interaction may need to be reported to the Federal Food and Drug Administration (FDA) in Washington, D.C.

You should never mix or store any of your medications in one drug container or bottle. One drug may interact chemically with the other, thereby affecting the possible potency of either one or both drugs. Storing multiple medications in one container can also lead to medication use "mix-ups". Many medications look similar in size, shape and color. Do NOT store your medications in car seats, glove compartments, windowsills, radiators or bathroom cub-boards. It is BEST to store your medications in a cool dry place (but not the basement !).

Never save any drug for later use. All drugs carry an expiration date. You can find the date on the drug container label. Some drugs carry very short half-lives. A half-life is a term used to describe the amount of time required for a specific amount of substance (drug, chemical etc.) to undergo a change in its chemical structure. Drugs tend to deteriorate chemically after passing their expiration date. Therefore using an "old" drug can be very harmful to you and potentially DANGEROUS resulting in an unnecessary adverse reaction.

On the next page we'll address concerns regarding adverse reactions and other prescription basics. There are a number of medications that can induce and aggravate various forms of dystonia. We will review these medications in later sections of this guide.

Next lets review basic Drug Physiology.

JOT DOWN ANY QUESTIONS HERE.....

CHECK OUT THESE WEB SITES :

<http://www.spasmodictorticollis.org/>
<http://www.care4dystonia.org/>

Interested in more medical information ?

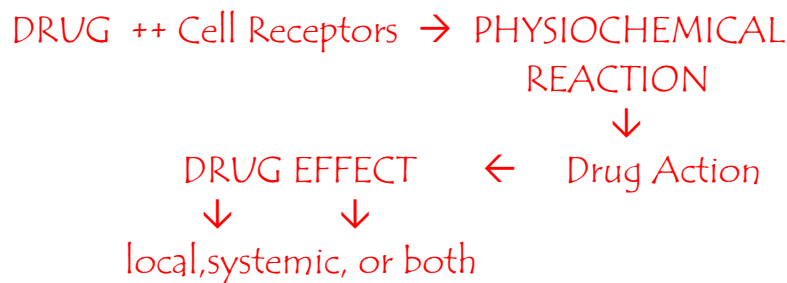
Check out

<http://www.medline.com>

BACK TO PRESCRIPTION BASICS...

Explaining drug actions and reactions will be the focus of this section. The administration of any medication initiates a series of physiochemical events within the body.

The first event in this series is referred to as "drug action". A "drug action" occurs when a specific drug combines with cell receptors in your body. What follows as a result of this interaction is known as the "drug effect". A drug effect can be either local, systemic, or both. A local drug effect is one whereby the action of the drug is limited to one area and does not spread to other parts of the body. A systemic effect results when the drug affects multiple areas of the body.



An example of a drug that causes a local effect is the medication, Pepcid, used to treat heartburn. Pepcid acts on specific cells located in the stomach. An example of a drug causing systemic effects is the popular drug, Artane, used in the treatment of cervical dystonia. Although this drug helps to balance activity within the basal ganglia, the center for movement control in the brain; the drug can cause a multitude of effects including nervousness, dizziness, headache, agitation, forgetfulness, blurred vision, dry mouth, nausea, and urinary difficulties.

A drug that can precipitate both local and systemic effects is botulinum toxin but we will discuss these effects in a future brochure. Describing botulinum toxin may take several pages! The toxin is a complex drug with much potential in the treatment of a variety of medical conditions.

There are several factors that affect the action of a drug within your body.

①

ABSORPTION - A drug must be absorbed into the bloodstream before it can act within the body. Once absorbed it can circulate through the bloodstream. It can then exert its specific drug action.

②

DISTRIBUTION – Once absorbed, a drug moves from the bloodstream to a number of other body fluids and tissues to induce its beneficial actions. This is called drug distribution. The rate at which distribution occurs is different for everyone.

③

**DRUG
ELIMINATION**

or **METABOLISM** – Metabolism is defined as “the breakdown of a substance” into smaller parts. Most drugs are metabolized by your liver and/or kidney. You should be aware of the fact that if one has either liver or kidney disease, the metabolism of a medication can be altered.

KIDNEY OR LIVER DISEASE → DRUG METABOLISM MAY BE INCREASED or DECREASED. This can lead to accumulation of the drug in your body as well as potential harmful side-effects such as drug toxicity.

YOU SHOULD BE CLOSELY MONITORED BY YOUR PHYSICIAN IF YOU HAVE KIDNEY OR LIVER DISEASE.

In addition, be aware that not all people metabolize the same drug in the same manner. Nor does everyone experience the same effects. Each person reacts differently to medications because each person is different and unique from a genetic perspective.

④

AGE – Older individuals are more prone to develop unnecessary side-effects. Through the aging process diminished liver and kidney function as well as a lower body mass can develop over time. The distribution of a drug within the body varies according to varying body masses. Often elderly patients will require lower medication doses as compared to younger individuals. This same concept applies to young infants and children.

A few words about **ADVERSE EFFECTS**...

Any drug effect that is **NON-THERAPEUTIC** is regarded as an “adverse reaction”. Reactions can occur unexpectedly and can be potentially harmful. Some reactions can be tolerable; others cannot and the medication then should be discontinued. You should never stop or discontinue taking a prescribed medication without informing your doctor about your intentions to do so **FIRST**.

KEY POINTS and HELPFUL HINTS :

- Learn the trade name and generic name of all medications that you are taking.
- When filling a prescription make sure that you understand when and how you are supposed to take the medication.
- If you are unsure about dosages, clarify them with your doctor.
- Utilize your local pharmacist. They have an immense amount of knowledge regarding medications, side-effects, drug actions, precautions, and drug-drug interactions.
- Be aware of any allergies to foods, iodine, shellfish and other substances.
- Carry a current list of all your medications with you on a daily basis.
- Store medications properly.
- Purchase your medications at the same pharmacy.
- Never discontinue a drug- prescribed or over-the counter products- suddenly.
- Follow physician instructions.
- Inform your family of the medications you are taking.
- Always ask questions; it is better to ask than not to ask.
- Keep a "prescription dairy", record any unusual drug effects.
- Inform your doctor of any side-effects(drug reactions) immediately.
- Never share medications.
- During travel, store your drugs in your carry-on luggage.

Purchase a medication reference book. Many are available in local bookstores. Check them out !

Although the above list sounds rather simple and basic, we cannot over-emphasize the importance of the content of this list.

Taking medications correctly can enhance "drug action" and "drug effect" and certainly reduce adverse reactions. Become a informed medication consumer !

Area for Questions:

ARTANE : ANTICHOLINERGIC BASICS

In this section we will provide you with important information concerning the use of Artane ®(trihexyphenidyl) in spasmodic torticollis and other forms of dystonia.

Dystonia is a syndrome of sustained muscle contraction(s) that frequently cause twisting and repetitive movements or abnormal postures (Fahn, 1988). Approximately 25% of patients with symptomatic dystonia are due to various degenerative neurologic conditions and environmental causes (Mardsen, 1990). The etiology (cause) of cervical dystonia or ST remains unclear, but there has been much progress in clarifying the genetic abnormality in families with inherited adult-onset cervical dystonia; linkage to chromosome 18p has been demonstrated in one family. The DYT1 locus has been excluded in two other families (Dauer, et al., 1998). Painful trauma to the neck and vestibular abnormalities are two additional theories proposed recently by scientists. Thus far, no specific cause for ST has been identified.

Individuals with dystonia have been treated with Artane since the early 1980's. One of the first published reports pertaining to the use of Artane and dystonia was published in 1979 by Dr. Stanley Fahn, M.D. Artane though has been on the pharmaceutical market since 1949. We were not able to obtain any historical information about the discovery of Artane, despite an intense search through MEDLINE and through telephone contact with the drug's manufacturer, Lederle Laboratories, a subsidiary of Wyeth-Ayerst Laboratories. We did review over 1,000 published article abstracts dating back to 1979 in preparation for this section !

1-800-934-5556 is the telephone number for the Medical Affairs Department at Wyeth-Ayerst Laboratories. One can easily inquire about Artane by speaking to one of their helpful product coordinators.

Notes:

Have Questions, Ask Us....

As mentioned previously, several research studies have been published about Artane and dystonia. Often large doses are required for the treatment of dystonia (Fahn, 1983). Approximately 50% of children and 20 to 40% of adults with dystonia experience moderate to marked improvement (Lang, 1989). Children and adolescents appear to tolerate larger doses of this medication as compared to adults.

Artane belongs to a group of drugs classified as "ANTICHOLINERGIC" agents. Other medications in this group include : biperiden (Akineton®), procyclidine (Kemadrin®), benzotropin (Cogentin®) and diphenhydramine (Benadryl®). These drugs alter the release of the neurotransmitter, acetylcholine, thus relieving muscle rigidity. The action duration of these drugs varies and people may tolerate one drug better than another. After long-term use, patients may become resistant to their beneficial effects. Sometimes either increasing the dose or using another drug may restore drug responsiveness. No specific anticholinergic agent has been found to be more beneficial from another.

Therapy with Artane is initiated at low dosages which are increased gradually until positive benefits are obtained or unacceptable side-effects occur. If Artane is to be stopped, it should be discontinued slowly. Gimenez-Roldan, et al. describe a case of a 64 year old woman with blepharospasm, oromandibular dystonia ("jaw dystonia"), dysphonia and ST developing sudden breathing difficulties after sudden withdrawal of Artane. The patient required emergent hospital care. She recovered after anticholinergic therapy was restarted. Never stop any medication on your own without consulting with your doctor first.

Here's what you need to know about Artane:

PRECAUTIONS:

Use cautiously if you have a medical history that includes glaucoma, stomach ulcers, enlarged prostate and bladder abnormalities, high blood pressure, kidney or liver disease, myasthenia gravis or heart rhythm irregularities.

Anticholinergic drugs can make you sweat less and cause your body temperature to rise. Be careful during hot weather, while you are exercising, or if using a sauna or whirlpool. Artane can cause drowsiness. Be careful if you are driving, using machinery, or doing other dangerous jobs that require concentration.

SIDE-EFFECTS: Call your doctor immediately if you develop: confusion, agitation, memory loss, weakness, blurry vision, stomach or abdominal pain, pain upon urinating, fast or irregular heartbeat. Additional side-effects include dry mouth, drowsiness, nausea, nervousness, and skin rash.

ROUTE: Both oral tablets and liquid forms are available.

Sustained-release caplets are also available. I was able to find one scientific report about the use of this form of Artane in dystonia.

ONSET OF ACTION: Varies among individuals.

PEAK ACTION: Occurs in 60 to 90 minutes.

HELPFUL HINTS:

If stomach upset occurs, take Artane with food.

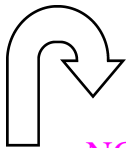
Avoid the use of alcohol when taking Artane.

Consult a dentist if dry mouth interferes with wearing , inserting, or removing dentures.

Obtain periodic eye exams.

Keep a prescription side-effect diary.

Ask questions about dosages and dosing schedules.



NOTES.....

Several years ago a research study investigated the use of Benadryl® in several patients with torticollis. Study results were mixed. For more information

ASK YOUR PHYSICIAN about this study or check www.MEDLINE.com

References:

Burke RE, et al., Torsion dystonia: Double-blind prospective trial of dosage trihexyphenidyl. NEUROLOGY 36 : 160-164, 1986

Dauer WT, et al. Current concepts on the clinical features, aetiology and management of idiopathic cervical dystonia, BRAIN 121 (Pt 4): 547-60, April 1998.

Fahn S. Concept and classification of dystonia. ADVANCES IN NEUROLOGY 50 : 1-8, 1988.

Fahn S. High dosage anticholinergic therapy in dystonia. NEUROLOGY 33: 1255-61, 1983.

Gimenez-Roldan S., et al. Life-threatening cranial dystonia following trihexyphenidyl withdrawal. MOVEMENT DISORDERS 4(4): 349-53, 1989.

Lang AE. Drug treatment of dystonia. ADVANCES IN NEUROLOGY 50:313-21, 1989.

Mardsen CD, et al. The dystonias. BRITISH MEDICAL JOURNAL 300: 139-144, 1990.

Samie MR. Sustained-release anticholinergics in dystonia: case report. NEUROLOGY 37; 885-6, May 1987.

The Physician's Desk Reference. 1999. A Wealth of Information...

The above references are available on the Internet and at your local medical library.
Check them out !

Next Drug to learn about is Klonopin® 

DYSTONIA MED FACTS...

LEARN about the drugs prescribed to You...

Healthy Living.....

CLARIFYING KLONOPIN....

Trade Name(s): Klonopin®, Paxam®, Rivotril®

Generic Name: Clonazepam

How supplied : 0.5 mg, 1 mg, 2 mg tablets

Uses: Relieves muscle spasms, reduces anxiety, sedative

Action : A Benzodiazepine that facilitates neurotransmission

Route : oral, scored tablets

Onset of Action : unknown

Peak Action : 1 to 2 hours

Duration of Action : unknown, precise mechanism of action unclear

Maximum recommended daily dosage not to exceed 20 mg/day.

Side- effects : Drowsiness (occurs in 50% of patients)

Slurred speech

Behavioral disturbances (more frequent in children)

Tremor

Agitation

Palpitations

Sore gums

Abnormal eye movements

Constipation

Nausea or change in appetite

Urine retention

Rash

Interactions : Avoid use with other central nervous system drugs and alcohol.

Drug can elevate liver function tests. Have these tests checked twice a year during routine office visits with your internist.

Clarifying Klonopin....

Interactions : Never withdraw or stop this or any other drug suddenly.

Notify your physician if any side-effects occur immediately.

Monitor blood levels of this drug,

Therapeutic blood levels of Klonopin are 20 to 80 ng/ml.

Gradual withdrawal of this drug is essential. Over time, this drug may not work as well.

Benzodiazepines may produce psychological and physical dependence.

Consult with your physician about any questions you may have regarding this medication or any other drug.

You , as an ST'er and human being, deserve the very best that health care has to offer.

Next Drug : Zoning in on BACLOFEN®

DYSTONIA MED FACTS.....

HERBAL NEWS... On the side news...

A increasing number of Americans are using herbal products for preventive and therapeutic purposes. Approximately 25% of Americans are utilizing alternative herbal remedies but only 70% of these individuals inform their physician of such use. Here are a few important comments that you should be aware of if you are using herbal remedies to help control your dystonic symptoms :

- Herbal products are not rigorously tested and thus cannot be marketed for the diagnosis, treatment, cure or prevention of disease.

- Side Effects of Select Herbal Products

Ginkgo biloba - Bleeding

St. John's Wort - Gastrointestinal disturbances, fatigue, dizziness, confusion, dry mouth, photosensitivity

Ephedra (ma huang) - High blood pressure, insomnia, nervousness, TREMOR, headaches, seizures, stroke, heart attacks and altered heart rhythms, kidney stones

Kava - Sedation, TORTICOLLIS and other dyskinesias, painful twisting movements of the upper body (sounds like dystonia ??), rash

HERBAL DRUG INTERACTIONS :

Ginkgo biloba - Aspirin, warfarin (Coumadin®), ticlopidine (Ticlid®), clopidogrel (Plavix®), dipyridamole (Persantine®), garlic, vitamin E

St. John's Wort - Antidepressants

Ephedra- Caffeine, decongestants, stimulants

Ginseng - Warfarin (Coumadin)

Kava- Sedatives, sleeping pills, antipsychotic medications, alcohol

The manufacturers of these products are not required to submit proof of safety and efficacy to the U.S. Food and Drug Administration before marketing. For this reason, adverse effects and interactions are largely unknown. Therefore, learn as much as you can about any herbal product that you are interested in taking. Always inform your doctor about the use of herbal remedies. Remember that the "gist" of this information is to PREVENT and AVOID an unnecessary interaction or side-effect.

A lists of herbs and their uses can be obtained from your pharmacist but Ask Questions first !

Reference: American Family Physician (Vol.59, no.5.) 1999 March.

NOTES.....NOTES.....NOTES.....NOTES...NOTES...NOTES...

ZONING IN ON BACLOFEN

BACLOFEN ®(Lioresal)

Baclofen is a central-acting muscle relaxant.

USES: Spasticity especially relief of spasms and associated pain and muscle rigidity. Highly effective in the treatment of spasticity related to spinal cord injuries, cerebral palsy and multiple sclerosis. Relieves spasms related to both primary and secondary dystonias in some cases.

ACTION: Baclofen is structurally similar to the neurotransmitter γ -amino butyric acid (GABA) and may exert its effects by stimulating GABA Beta receptors in the brain. Appears to reduce transmission of impulses from spinal cord to skeletal muscle.

Duration of Action : Variable and dose-dependent. Drug is rapidly absorbed with peak serum levels reaching within 2 hours, half-life is 3 to 4 hours.

Available forms : oral, intrathecal (so-called the Baclofen pump)

SIDE-EFFECTS : drowsiness, weakness of the arms or legs, dizziness, lightheadiness, fatigue, nausea, vomiting, blurred vision, confusion, insomnia, urinary frequency, changes in blood pressure, slurred speech

DOSAGE: Drug dosage is individualized. Therapy is started at a low dosage and is increased gradually until optimal effects is seen (usually 40 mg to 80 mg per day) Total daily dose should not exceed 80 mg.

PRECAUTIONS : Do NOT increase dose on your own without your physicians knowledge.

Use caution while driving or performing other tasks that require alertness.

Avoid alcohol and other CNS depressant use.

Do NOT discontinue therapy except on the advice of your physician. Abrupt withdrawal can lead to hallucinations and other effects.

Can be taken with food which may decrease stomach upset.

Easing Muscles...

There are several muscle relaxants that may help in easing constant muscle spasms. Lets take a look at each one...

FLEXERIL® (Cyclobenzaprine)

USE: This medication relaxes muscles and relieves pain and discomfort associated with strains, Sprains, spasms (hence its use in dystonia) and other related muscle injuries,

How Supplied: Oral

ACTION: Unknown. Relieves skeletal muscle spasm of local origin without interfering With muscle function.

PEAK Action : 5 hours, onset and duration of action is unknown.

PRECAUTIONS : Before taking this drug, inform your doctor if you have glaucoma, an overactive thyroid gland (hyperthyroidism), heart disease, difficulty urinating and of Any allergies you may have.

Inform your doctor if you are pregnant.

Alcohol adds to the dizziness and drowsiness caused by this drug.

Limit alcohol intake.

Do not use longer than 3 weeks unless otherwise specified to do so by your doctor.

SIDE-EFFECTS: Stomach upset

Heartburn, constipation

Headache

Dizziness, DROWSINESS, dry mouth

Rash, itching

Light headiness

HELPFUL HINTS :

Many of the side-effects occur during the first few days as your body adjusts to the drug.

When rising quickly from a sitting or lying position, do so slowly and cautiously.

Flexeril Info con't...

This drug provides temporary relief and must be used in addition to rest, physical Therapy and other measures.

Because of the risk of liver damage with long-term use, therapy should be discontinued within 45 days if benefits aren't seen. The amount of relief determines whether dosage can be reduced.

Store at room temperature away from sunlight and moisture.

NOTE : In some individuals the effects of drowsiness can be SEVERE and prolonged. Thus, use this drug cautiously.

SOMA ®(carisoprodol)

USES: To reduce muscle spasms and muscle tension

HOW SUPPLIED : Oral

ACTION: Unknown. Appears to modify central perception of pain without modifying pain reflexes. Effects may be related to its sedative effects.

PRECAUTIONS : Watch for unusual reactions after 4th or 5th doses.

Drowsiness is transient and temporary.

Best to take with food. Avoid alcohol use.

SIDE-EFFECTS: Drowsiness, dizziness, insomnia

Tremor, changes in blood pressure, nausea, stomach upset

Agitation, headache, depressive reactions, hiccups, rash

ROUTE: oral-tablet form only

ONSET of ACTION: 30 minutes

PEAK Action : 4 hours, duration is 4 to 6 hours

HELPFUL HINTS : Avoid combining drug with other CNS (central nervous system) medications. Avoid changes in posture if dizziness occurs.

ROBAXIN® (Methocarbamol)

USES: Can help to relieve flexor spasms, a type of involuntary muscle movement or Tightness called spasticity.

HOW SUPPLIED : Injection and tablet forms

ACTION : Blocks signals from the brain (or acting directly on muscles).

ROUTE : Injection or oral forms available

ONSET of ACTION : 30 minutes or so

PEAK Action : 2 hours

PRECAUTIONS : Take drug with food or milk at evenly spaced intervals or as ordered.
A oral metallic taste may develop, urine may change color
Avoid injectable form as the drug is irritating to veins.
Be-aware of sensitivity reactions such as rash and fever, report these immediately to your physician.

SIDE-EFFECTS: Drowsiness, light headiness
Headaches, fainting, blurred vision
Double vision, conjunctivitis ("pink eye")
Stomach upset, metallic taste, discoloration of urine
Itching, rash

HELPFUL HINTS : Avoid use if you have a history of seizures or kidney problems.
Some diagnostic laboratory tests may be altered, investigate these with your physician.

Another muscle relaxant in use today is Dantrium®

Ask for drug information print-outs when filling your prescriptions.

CHECK OUT www.RxList.com !

ANTICONVULSANTS

Tegretol ® (carbamazepine)

USE: Limit seizure/spasticity activity

ACTION: Unknown. Thought to stabilize neuronal (nerve) membranes by altering the crossing of certain ions across cell membranes during nerve impulse generation.

PEAK Action: 1.5 to 12 hours, onset and duration of action is unknown.

ROUTE: oral tablet and liquid forms are available.

PRECAUTIONS: May interfere with pregnancy test results.

Avoid use with the drug, lithium.

Don't use together with depressant or anticholinergic effects.

Avoid use with the herb ,psyllium seed; may cause stomach upset.

Never discontinue drug on own.

SIDE-EFFECTS: Dizziness, vertigo, drowsiness, fatigue
Worsening of seizures, gait (walking) difficulties
Changes in blood pressure
Aggravation of heart disease
Dry mouth, double vision, blurred vision
Nausea, stomach upset
Urinary retention
Fever, chills

HELPFUL HINTS : Not for use in patients with a history of sensitivity to tri-cyclic antidepressants or a history of bone marrow disease or changes.
Should not be used together with MAO inhibitors— a class of psychiatric medications.
May alter liver and thyroid disease laboratory tests. Have these tests checked.
Sustained-release extended tablets should not be chewed or crushed.
Some formulations may harden if stored in areas of moisture.

Neurontin® (gabapentin)

USE : Interferes with GABA action but action is unknown; used to control seizures and tremors.

ACTION: Exact mechanism unknown.

HOW SUPPLIED : oral or capsule form.

ROUTE: oral

PEAK ACTION : Onset, peak and duration of action unknown to-date

PRECAUTIONS: If drug therapy is to be discontinued, do so gradually.
Drug doesn't alter other anticonvulsant drug levels.

SIDE-EFFECTS: Fatigue, dizziness, somnolence
Tremor, nervousness, amnesia, depression
Twitching
Incoordination, swelling, double vision
Nausea, stomach upset, increased appetite, weight gain
Back pain, myalgias (muscle aches)

HELPFUL HINTS : Can cause false positive laboratory tests, check these with your doctor.
Dose should be taken at bedtime to reduce sleeping problems.
Do not use together with antacids, separate use by 2 hours.

Got Questions ??? Ask Us !
www.care4dystonia.org

Mysoline ®(primidone)

USE: Used to treat partial-complex seizure-like activity.

HOW SUPPLIED : Oral and liquid forms available.

ACTION: Unknown.

PEAK Action : 3 to 4 hours, onset and duration unknown

PRECAUTIONS: Do not stop drug suddenly.

Don't confuse primidone with prednisone- a steroid.

Full therapeutic response may take 2 weeks or more.

SIDE-EFFETS: Drowsiness

Gait (walking) disturbances

Emotional disturbances

Vertigo (ringing in the ears)

Double vision, nystagmus

Anorexia, nausea, vomiting

Frequent voiding

Anemia

Abnormal liver tests

Rash

HELPFUL HINTS : OBSERVE for toxicity. Can interfere with action of other drugs.

If using liquid form, shake the suspension well.

Notify your physician of any side-effects immediately.

Therapeutic blood levels of mysoline is 3 to 12 mcg/ml.

Serum blood chemistries should be monitored every 6 months.

NOTES:

Depakote ®(valproic acid)

USE: To control simple and "absent" seizures

ACTION: Unknown. Probably increases GABA levels in the brain.

HOW SUPPLIED : Oral tablets, capsules and syrup. Also available in injectable form.

PEAK Action: 15 min to 4 hours, onset and duration of action unclear.

PRECAUTIONS : Valproic acid can interfere with many medications. It is best if you are under the close supervision of a physician when taking this drug.

Ask your pharmacist for a list of drug-drug interactions.

Serious liver toxicity can occur with this drug.

Avoid alcohol use.

SIDE-EFFECTS: Sedation, emotional upset, depression, psychosis

Hyperactivity, TREMOR, incoordination, gait disturbances

Nystagmus, double vision

Nausea, vomiting, indigestion, diarrhea, stomach "cramps"

Constipation, increased appetite

Pancreatitis (an emergency –seek treatment)

Bruising, elevated liver enzymes, weight gain,

HELPFUL HINTS : Monitor liver and bleeding function tests.

Many of the side-effects do not occur due to valproic acid but its interactions with other medications.

Avoid sudden drug withdrawal.

Notify your doctor if tremors develop.

Therapeutic blood levels for Depakote is 50 to 100 mcg/ml.

Do not chew capsules.

Syrup should not be mixed with carbonated beverages.

A Few Words about Anti-depressants

Antidepressants are sometimes prescribed to help alleviate the stressors associated With ST/Dystonia. However , when used in combination with other anti-spastic drugs, one may acquire an improved response. This may lead to a lessening of dystonic symptoms thereby reducing some symptoms.

There are many anti-depressants on the market today including :

Paxil®

Celexa®

Trazadone® , Zoloft®, Prozac®, Effexor®, Amitriptylene®
and many others.

Each antidepressant works differently in each individual. Sometimes, finding the right drug for you may take the form of "trial and error". Every person adjusts to this group of medications differently. Some may find the use of an anti-depressant useful in their dystonia regimen. Others may not. Talk this over with your physician.

CAUTION : There have been reports describing the development of ST with the use Prozac. Clarify this with your physician.

Signs of Depression include :

Crying

Fatigue and lethargy

Nervousness

Irritability

Change in appetite

Change in weight

Insomnia or sleeping too much

Feelings of helplessness/hopelessness

Lack of social interests

If you have any of these signs or feelings, ASK for HELP.

Inform your healthcare provider and review your treatment strategy.

Seek individual or group support.

YOU ARE NOT ALONE.....Join a Support Group !

ANTI-ANXIETY DRUGS..... ANTI-ANXIETY DRUGS.....ANTI-ANXIETY.....

Some of the drugs being used today to control ST/Dystonia are not necessarily being used to control your anxiety or level of "nervousness" but to reduce dystonia symptoms. Common drugs include:

- Xanax®(alprazolam)
- Ativan®(lorazepam)
- Valium®(diazepam)
- Buspar®(buspirone)
- Clonazepam®(clonopine)

We've already taken a look at Clonopine, let's now take a look at Ativan and Valium. All these drugs are classified as "controlled substances". Your doctor will write out your prescription using a special form.

ATIVAN®(lorazepam)

USE: Depresses the CNS at the limbic and sub cortical levels of the brain.

HOW SUPPLIED: Oral tablets, liquid and injectable forms

ACTION: Unknown. Classified as a "benzodiazepine", it probably potentiates the effects of GABA, a neurotransmitter released in the brain, and slows down the CNS.

PRECAUTIONS: Don't stop drug suddenly. This 'basic' rule applies to all benzodiazepines.

The possibility of drug abuse and addiction exists with this class of drugs.

Drug should be avoided in the first trimester of pregnancy.

If you are taking the drug, digoxin, serum levels of digoxin may rise and you may become "dig-toxic". (EMERGENCY)

Smoking decreases the effectiveness of this drug and other benzodiazepines.

SIDE-EFFECTS: Drowsiness, amnesia, insomnia, sedation, agitation, weakness, unsteadiness, depression, low blood pressure, nausea, change in appetite, elevated Liver function tests, headache and disorientation, suicidal tendency.

Ativan info cont'd.

HELPFUL HINTS : Should not be used if you have been diagnosed with a form of glaucoma called "angle closure glaucoma".

Use cautiously if you have lung, kidney or liver disease.

Monitor kidney and liver function tests on a periodic basis.

Avoid use of alcohol when taking any type of benzodiazepine including Ativan.

Avoid smoking.

ACUTE WITHDRAWAL SYMPTOMS CAN OCCUR IF DRUG is stopped suddenly. Suicidal tendencies have been reported.

NOTES....NOTES....NOTES....

VALIUM® (diazepam)

Valium helps reduce the CNS response and reduce anxiety levels. Side-effects and precautions to be taken are the same.

PEAK Action : 2 hours with duration of action being 3 to 8 hours.

Valium can induce tremor. Inform your doctor if this symptom should occur. Alcohol should be avoided. Use sugarless hard candy or gum to relieve dry mouth. Again, be aware that withdrawal effects can occur if the drug is stopped suddenly.

DO NOT STOP ANY OF YOUR DRUGS WITHOUT THE APPROVAL OF YOUR PHYSICIAN...

BUSPAR®INFO....

Buspar®(buspirone hydrochloride) may inhibit neuronal firing and reduce symptoms of spasmodic torticollis; however this drug is generally used for short-term use. It is less sedating than other drugs and does not cause serious functional impairment or other Central Nervous System (CNS) effects. But be aware that CNS effects such as drowsiness, dizziness, insomnia, nausea and dry mouth may occur at an unpredictable rate in some individuals.

Buspar is not an anticonvulsant or skeletal muscle relaxant; its use is limited to the Treatment of anxiety.

We know that anxiety can worsen our ST or other dystonia symptoms in some of us. The less anxiety, the better !

Signs of improvement with Buspar usually are evident within 7 to 10 days; optimal results are achieved after 3 to 4 weeks of therapy.

Only available in oral or "pill" form.

Xanax®(alprazolam) Info

This drug slows the CNS at the limbic and subcortical areas of the brain. This is a controlled substance therefore requires a special prescription from your doctor. Dosage should be reduced in the elderly because they may be more susceptible to the adverse CNS effects.

Do not withdraw drug suddenly.

Abuse or addiction is possible.

Withdrawal symptoms may occur.

Do not combine drug with alcohol or other depressants.

Drug should not be prescribed for everyday stress or for long-term use.

Compared to other benzodiazepines, Xanax has a lower incidence of lethargy than other drugs in this class.

Other anti-anxiety drugs include Tranxene®, Paxipam®, Serax®, Centrax®.

The Botulinum Toxin Zone...

Botulinum toxin, a biological agent and toxic protein known to cause Botulism—a form of “food poisoning”, has been in use for over 15 years in the treatment of dystonia and other medical conditions. Seven serotypes or forms of the toxin exist—types A,B,C,D,E,F and G.

Currently forms A (Botox®) and botulinum toxin B are in use in the treatment of dystonia. Botulinum toxin F has been used and investigated in a number of clinical trials with mixed study results.

BoTox® is manufactured by Allergan in the U.S. (www.Allergan.com)

Botulinum toxin A in other countries is made by Ipsen and marketed as Dysport®.

Botulinum toxin B is being developed by Athena Neurosciences, Inc.

As of the printing of this guide no final ruling from the FDA regarding the use of this toxin has been finalized. However, the toxin's potential name may be MYOB-LOC.

Botulinum toxin acts to block the release of acetylcholine, a neurotransmitter responsible for muscle contraction activation, when injected into over-active muscles. Toxin A has proven to be the most effective agent in the relief of focal and segmental dystonias. Its dose must be adjusted to provide the precise degree of weakness needed to overcome dystonia. Injected muscles can still contract but to a lesser degree after the injection process.

BOTULINUM TOXIN TEMPORARILY WEAKENS MUSCLES.

BOOSTER INJECTIONS SHOULD BE AVOIDED to decrease the risk of antibody formation. Once antibodies form, the effectiveness of botulinum toxin is lost.

EMG USE is HIGHLY RECOMMENDED for proper muscle identification.

Effects are usually felt greatest for a two to six week period after injection.

Injections should be given every 10 to 12 weeks (average every 3 months).

Botulinum toxin should be used with extreme caution in people diagnosed with myasthenia gravis or other neuromuscular disease. Those individuals taking anti-coagulants (blood “thinners”) or certain antibiotics such as

Garamycin®

Kentrex®

should also be cautious. The following Guidelines

were

Neo Tab®

originally developed in 1998. Check with

your

DOPAMINE BLOCKING AGENTS
DOPAMINE DEPLETING AGENTS

Tetrabenazine®
Lithium®
Clozapim®
Olanzapin®

These groups of agents have shown promise in the management of symptoms in some patients. Experience with Olanzapin has been somewhat limited to-date. Tetrabenazine (TZB), available in other countries but not in the U.S., is a Catecholamine depleting agent with varied blocking characteristics. Studies have documented its beneficial usefulness in the control of primary and secondary Dystonias.

TZB does have two problematic side-effects:

depression and drug-induced parkinsonism.

These side-effects resolve once the drug is stopped.

These are serious side-effects thus one must weigh out the drug's benefits vs side-effects and dystonic symptoms.

ASK QUESTIONS...OBTAIN AS MUCH INFORMATION about TZB before beginning a trial of this drug.

The drug's distributor is Cambridge Laboratories in England.

The addition of Lithium® may minimize the side-effects of TZB and improve its beneficial effects.

QUESTIONS...QUESTIONS.....



A Few Words about Anti-parkinsonian Meds...

Certain forms of dystonia can be classified as “secondary” dystonias. This means that the dystonia is caused by another medical problem—neurological disorder, Wilson’s Disease, metabolic deficiencies etc. Dystonia has been classified according to age of onset, etiology (idiopathic, primary, secondary) and clinical signs.

Often, If a person presents with unusual or “un-classic” dystonia and their age is less than 30, a trial of antiparkinsonian medications including SINEMET®, are tried. If their dystonic symptoms improve they may then have a form of dystonia called “dopa-responsive dystonia”. Improvement in dystonia symptoms often are quite striking and immediate.

You can learn more about Parkinson’s disease and the use of Sinemet in the guide UnMasking Parkinson’s Disease, distributed by The Bachmann-Strauss Dystonia & Parkinson Foundation, Inc. (<http://www.dystonia-parkinsons.org/>)

An Area for Your **Questions** :

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Join US in Making A Positive Change....

Please reread our medical disclaimer.

Baclofen info cont'd...

Kidney problems, seizures, psychiatric or brain disorders (stroke), ulcers or any drug allergies.

Elderly individuals may be more sensitive to this drug and its effects. Use cautiously.

This drug should only be used if clearly needed during pregnancy. Discuss the risks and Benefits with your doctor.

Do not allow anyone else to use this drug.

Store at room temperature away from heat and moisture and heat.

Do not store in the bathroom.

Notes:

Write down your dosage here: _____

Times to take the drug: _____

Beyond Year 2000...Hopes and Predictions about ST/Dystonia from Us....

- ◆ Standards of Care are established for physicians treating dystonia and other movement disorders. This will ensure consistency in care for those with ST/dystonia.
- ◆ A central referral "center " is established to ensure proper care and to provide direction for dystonia care to newly diagnosed individuals.CENTER of EXCELLENCE....
- ◆ Increased use of complimentary medicine in the management of dystonia.
- ◆ Identification of gene markers for all types of dystonia.
- ◆ The "Decade of the Brain" will continue.
- ◆ Research in the area of neuromodulation will increase.
- ◆ Continued increased awareness of dystonia via the media -local and national levels.
- ◆ Increased training and refinement of selective denervation at multiple medical centers.
- ◆ Shift in the focus and care to the person/family with dystonia/ST to a more psychosocial or holistic approach.
- ◆ Increase in the number of movement disorder specialists.
- ◆ Creation of the "movement disorder nurse clinician" role at major movement disorder centers/clinics to decrease fragmentation of care.
- ◆ Refinement in the use of botulinum toxin and its variants.
- ◆ Progress in deep brain stimulation in the treatment of dystonia.
- ◆ The arrival of a spokesperson from the entertainment industry area (we're working on this ...) to serve as a representative for people with ST/dystonia. There must be a couple more "Michael J. Fox's " out there for us ?
- ◆ Increased literary information about dystonia, research and other items written at levels understood by the average individual with dySTonia.
- ◆ Prediction of those most likely to develop botulinum toxin antibodies- a blood serum test. Identification of long-term toxin side-effects ?
- ◆ Increased awareness for genetic testing for ST/dystonia.
- ◆ Initiation of long-term demographic studies of ST'ers and other people with other forms of dystonia to gain more specific information of "who we are "? EPIDEMIOLOGY !
- ◆ Increased corporate funding for care and cure initiatives.
- ◆ Exchange of ideas and information with other dystonia-related groups, pharmaceutical companies , nursing and physician organizations.

Submitted originally to DySTonia, Inc, newsletter 1999 Beka Serdars, RN

JUST FOR FUN....Reflective Thoughts....

- ◆ JUST FOR FUN...Reflective Thoughts...
- ◆ He who laughs last, thinks slowest.
- ◆ A day without sunshine is like, well, night.
- ◆ I just got lost in thought. It was unfamiliar territory.
- ◆ I feel like I'm diagonally parked in a parallel universe.
- ◆ I wonder how much deeper the ocean would be without sponges.
- ◆ Honk if you love peace and quiet.
- ◆ Despite the cost of living, have you noticed how it remains so popular.
- ◆ If You can't have everything, where would you put it ?
- ◆ I wished the buck stopped here, as I could use a few.
- ◆ Learn the most about your medications.

INFORMATIVE HEALTH WEB SITES:

[Http://www.spasmodictorticollis.org/](http://www.spasmodictorticollis.org/)

[Http://www.care4dystonia.org/](http://www.care4dystonia.org/)

[Http://www.neurologychannel.com](http://www.neurologychannel.com)

[Http://www.medtronic.com](http://www.medtronic.com) for DBS info

[Http://www.neurochannel.com](http://www.neurochannel.com)

[Http://www.wemove.org/](http://www.wemove.org/)

[Http://www.Allergan.com](http://www.Allergan.com)

[Http://www.neurocast.com](http://www.neurocast.com) click to archives and then dystonia

Send Us Your Comments and Suggestions.

We've included many of the most common medications being used today in the field of dystonia. If we have missed one or another, please let us know so that we can add a write-up of the drug in a future edition of Dystonia Med Facts.

You can write , e-mail, fax or call us with your comments and suggestions.

We look forward to hearing from you !

DySTonia, Inc.

P.O. Box 28

Mukwonago, WI 53149

Phone- 715-258-8756

Toll Free- 1-888-455-4588

Fax- 715-258-8757

Web Site- www.spasmodictorticollis.org/

E-mail- info@spasmodictorticollis.org

Care4Dystonia, Inc.

Beka Serdars, RN

440 East 78th Street

New York, NY 10021

Web Site- <http://www.care4dystonia.org/>

E-mail- info@aol.com

Order and Read the books about Dystonia :

[I'm Moving Two by Beka Serdars, RN](#) 200 pages of Insights...

View at <http://www.care4dystonia.org>

[I'm Moving On...Are U ? By Beka Serdars, RN \(2002\)](#)

_Coming soon— Sincerely Yours, Dystonia by Beka Serdars, RN