

# Medications for Youth with Disabilities

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# Objectives

- ◆ Benefits vs. the risks of using medications
- ◆ Terminology used by professionals when discussing medications
- ◆ Factual and non-biased resources for researching medications used to treat childhood illnesses and disorders
- ◆ What to expect from your health professional regarding the use of medication
- ◆ A parent's responsibility regarding monitoring a child's medications
- ◆ Resources in the community for more information about managing medications

# When to consider Rx

- ◆ **Bedwetting**-if it persists regularly after age 5 and causes serious problems in low self-esteem and social interaction.
- ◆ **Anxiety** (school refusal, phobias, separation or social fears, generalized anxiety, or posttraumatic stress disorders)-if it keeps the youngster from normal daily activities.
- ◆ **Attention deficit hyperactivity disorder (ADHD)**-marked by a short attention span, trouble concentrating and restlessness. The child is easily upset and frustrated, often has problems getting along with family and friends, and usually has trouble in school.

# When to consider Rx

- ◆ **Obsessive-compulsive disorder (OCD)**-recurring obsessions (troublesome and intrusive thoughts) and/or compulsions (repetitive behaviors or rituals such as handwashing, counting, or checking to see if doors are locked) which are often seen as senseless but that interfere with a youngster's daily functioning.
- ◆ **Depression**-lasting feelings of sadness, helplessness, hopelessness, unworthiness, guilt, inability to feel pleasure, a decline in school work and changes in sleeping and eating habits.
- ◆ **Eating disorder**-either self-starvation (anorexia nervosa) or binge eating and vomiting (bulimia), or a combination of the two.

# When to consider Rx

- ◆ **Bipolar (manic-depressive) disorder**-periods of depression alternating with manic periods, which may include irritability, "high" or happy mood, excessive energy, behavior problems, staying up late at night, and grand plans.
- ◆ **Psychosis**-symptoms include irrational beliefs, paranoia, hallucinations (seeing things or hearing sounds that don't exist) social withdrawal, clinging, strange behavior, extreme stubbornness, persistent rituals, and deterioration of personal habits. Psychosis may be seen in developmental disorders, severe depression, schizoaffective disorder, schizophrenia, and some forms of substance abuse.

# When to consider Rx

- ◆ **Autism**-(or other pervasive developmental disorder such as Asperger's Syndrome)-characterized by severe deficits in social interactions, language, and/or thinking or ability to learn, and usually diagnosed in early childhood.
- ◆ **Severe aggression**-which may include assaultiveness, excessive property damage, or prolonged self-abuse, such as head-banging or cutting.
- ◆ **Sleep problems**-symptoms can include insomnia, night terrors, sleep walking, fear of separation, or anxiety.

# Risk vs. Benefits

- ◆ Clinical practice must be guided by ethical principles
- ◆ Informed consent – serves to protect patient autonomy by ensuring patients are informed of the diagnosis, treatment options, alternatives to treatment, and risks and benefits of those options
- ◆ Consent to treatment must be given voluntarily and not be coerced by the physician

# Risks vs. Benefits

- ◆ Consenting person
  - ◆ Understand their medical situation
  - ◆ Understand seriousness of their condition
  - ◆ Understand the consequences of accepting or rejecting treatment
  - ◆ Be able to express a preference
  - ◆ Be capable of manipulating the provided medical information in a rational manner

# Risks vs. Benefits

- ◆ Children have a limited capacity to understand informed consent and medical treatment issues
- ◆ They need their caregivers/guardians to act in their best interests and provide informed consent

# Informed Consent Discussion

- ◆ Nature of the condition that requires treatment
- ◆ Nature and purpose of the proposed treatment and the probability that it will succeed
- ◆ Risks and consequences of the proposed treatment
- ◆ Alternatives to the proposed treatment and their accompanying risks and consequences

# Informed Consent Discussion

- ◆ Prognosis with and without the proposed treatment
- ◆ Possibility of unknown risks to the use of medication in children, especially when using novel or new medications or treatments in which the risks versus the benefits are uncertain

# Children

- ◆ Children 7 years or older must provide their assent to treatment
- ◆ Assent: general agreement to undertake the treatment

# Elements of Child Assent

- ◆ Helping child achieve a developmentally appropriate awareness of the nature of his/her condition
- ◆ Telling the child patient what to expect from the tests and treatments
- ◆ Soliciting a statement of the child's willingness to accept the recommended tests and/or treatment

# Risks vs. Benefits

- ◆ Informed consent and assent are ON GOING processes, not single events to be completed and then forgotten as treatment proceeds
- ◆ Physicians must repeatedly inform patients as to the benefits and risks of interventions if these change or become clearer over time, and be available to answer patient questions as these arise in the course of treatment

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# Potential Benefits

- ◆ Symptom Reduction and Improved Functioning
  - ◆ Improved school attendance and performance;
  - ◆ Improved family and peer relationships;
  - ◆ Decreased involvement with law enforcement and the juvenile justice system;
  - ◆ Decreased rates of substance use and abuse; and
  - ◆ Reduction in self-harm and suicide related behaviors.
- ◆ Prevention of Deep End Service Use
  - ◆ Decreased hospital admissions, institutional care, and other types of out-of-home placement.

# Medication Terminology

- ◆ Pharmacokinetics: study of what the BODY does to the drug
  - ◆ Drug concentration is related to drug dose, dosing frequency, absorption, distribution, metabolism, and excretion
  - ◆ Younger the child, more rapid the the metabolism compared to adults
- ◆ Pharmacodynamics: study of what the DRUG does to the body
  - ◆ Results in benefits to lessen the impact of the disease and treat symptoms
  - ◆ Can also result in side effects

# Medical Terminology

- ◆ Efficacy: capacity for beneficial change (or therapeutic effect) of a given intervention
- ◆ Effectiveness: extent to which a drug achieves its intended effect in the usual clinical setting
- ◆ Tolerability: degree to which overt adverse effects of a drug can be tolerated by a patient

# Pediatric variations in pharmacokinetics

- ◆ Children and Adolescents are not “little adults”
- ◆ Variations also depend on the drug, concomitant drug, patient’s health, and genetic variability
- ◆ In some cases they may require larger doses (mg/kg) compared to adults
- ◆ Faster metabolic rates; drug doses must be given in shorter intervals (more frequent dosing)
- ◆ By age 15 or so, children tend to develop adult pharmacokinetic parameters

# Researching Information

- ◆ American Academy of Child & Adolescent Psychiatry
  - ◆ [www.aacap.org](http://www.aacap.org)
- ◆ American Academy of Pediatrics
  - ◆ [www.aap.org](http://www.aap.org)
- ◆ National Institute of Mental Health
  - ◆ [www.nimh.nih.org](http://www.nimh.nih.org)
- ◆ National Alliance for the Mentally Ill
  - ◆ [www.nami.org](http://www.nami.org)

# Researching Information

- ◆ Children & Adults with ADHD (CHADD)
  - ◆ [www.chadd.org](http://www.chadd.org)
- ◆ National Attention Deficit Disorder Association
  - ◆ [www.add.org](http://www.add.org)
- ◆ Bipolar Disorders Information Center
  - ◆ [www.mhsource.com/bipolar](http://www.mhsource.com/bipolar)
- ◆ Depression in Children and Adolescents
  - ◆ [www.psychom.net/depression.central.children.html](http://www.psychom.net/depression.central.children.html)
- ◆ National Center for Learning Disabilities
  - ◆ [www.ncl.org](http://www.ncl.org)

# Researching Information

- ◆ Obsessive Compulsive Disorder
  - ◆ Obsessive Compulsive Foundation
  - ◆ [www.familymanagement.com/facts/english/facts60.html](http://www.familymanagement.com/facts/english/facts60.html)
- ◆ Tic Disorders and Tourette's Disorder
  - ◆ Tourette Syndrome Association

# What to expect

- ◆ Goals of an evaluation:

- ◆ Thoroughly evaluate and determine if diagnostic criteria are met for one or more disorder
- ◆ Ascertain medication target symptoms
- ◆ Determine if the disorder or target symptoms are responsive to medications
- ◆ Must be comprehensive and lead to treatment planning that includes psychosocial therapies and/or psychoeducational interventions

# What to expect

- ◆ Findings must be communicated in a manner that is free of medical jargon
- ◆ Sources of information
  - ◆ Information from multiple sources must be integrated into the comprehensive evaluation; (ex: parents, teacher, therapist, parapro)
  - ◆ Children and adolescents should be interviewed directly

# What to Expect

- ◆ Psychiatric Interview:
  - ◆ Chief Complaint
  - ◆ History of symptoms, including type, age of onset, impairment caused by them, and longitudinal course
  - ◆ Developmental history
  - ◆ Family history
  - ◆ Current and past treatments/what worked/didn't work
  - ◆ Current and past medications

# What to Expect

- ◆ Psychiatric Interview
  - ◆ School and educational history including presence of any associated learning disabilities
  - ◆ Review of any previous psychological and academic testing reports, if available
  - ◆ Medical history
  - ◆ Medication allergies
  - ◆ Labs if indicated

# What to Expect

- ◆ Psychiatric Interview:
  - ◆ Current medications
  - ◆ Any medical consultants or specialists involved in care

# Questions to ask your prescriber

- ◆ Why are you recommending this treatment and what are the alternative treatments, if any?
- ◆ What is the goal of the treatment being recommended and will it help us get the outcomes that we want? (Share the outcomes you want, such as improved school attendance and performance, less child and family distress, improved behavior and relationships with family and peers, improved functioning, and others.)
- ◆ How will we know if we are reaching our treatment goals?

# Questions to ask your prescriber

- ◆ How does the recommended treatment promote my child's strengths, capabilities, and interests?
- ◆ What are the risks and benefits associated with the recommended treatment?
- ◆ How does the recommended treatment work and what is involved?
- ◆ Is there research or evidence to support the use of this treatment? If so, are you following a manual that describes how it works?

# Questions to ask your prescriber

- ◆ Is there research showing that the recommended treatment works for families like ours? Tell us about the research supporting the recommended treatment.
- ◆ What training and experience do you have with the recommended treatment?
- ◆ If you are not recommending an evidence or research-supported treatment, why not?

# Questions to ask your prescriber

- ◆ How will our family be involved in the recommended treatment and how can we best support the treatment?
- ◆ What changes can we expect to see and how long will it take before we see these changes?
- ◆ How do we measure and monitor progress?
- ◆ What should we do if problems get worse or we do not see an improvement?

# Questions to ask your prescriber

- ◆ How do we reach you after hours or in an emergency, and if we cannot reach you, will someone else from your office be available. If so, who?
- ◆ Is the recommended treatment covered by our insurance and what is the cost?

# Questions to ask your prescriber

- ◆ Are there psychosocial interventions that might be tried before medication is used, or effectively used in combination with medication, which may help to lower the required medication dose?
- ◆ Does research support the use of the recommended medication for a child that is my child's age and with similar needs?
- ◆ How does medication fit within the overall treatment plan and how will we coordinate with other treatment, such as therapy, school behavior plans, and more?

# Questions to ask your prescriber

- ◆ What should we be looking for in changes in behavior, changes in symptoms, and who should we contact with questions about these changes and the medication?
- ◆ What are the potential risks and benefits of the medication and other treatment options, and what are the potential side effects?
- ◆ How will our family, our child, and the treating provider monitor progress, behavior changes, symptoms, and safety concerns?  
(Close monitoring is critical with all medications at all times, however, it is especially important when medication is started and when dosages are changed.)

# Questions to ask your prescriber

- ◆ How will we know when it is time to talk about stopping medication treatment and what steps need to be taken before the medication is stopped?
- ◆ How can we best develop a clear communication plan between our family and the treating providers (therapist and psychiatrist) to ensure open lines of communication?
- ◆ What if my child has a crisis and is hospitalized? Who can we contact in your office, especially if someone want to change medications?

# Monitoring at home

- ◆ Be clear on what time of day/how many times a day
- ◆ Keep medications in safe place, out of reach of small children
- ◆ Pair medications with routines such as brushing teeth or use a timer (phone) as a reminder
- ◆ Monitor teens who may begin to become more independent with taking their medications
- ◆ Consider pill boxes to avoid doubling up on meds

# Giving medications to young children

- ◆ Medicines work best when given correctly
  - ◆ Right dose
  - ◆ Right time
  - ◆ Right way
- ◆ The more you learn about your child's medicine and the more careful you are, the safer your child will be.
- ◆ Always feel free to ask questions about your child's medicine.

# What should I know?

- ◆ Each time a new medicine is prescribed, to ask the doctor or pharmacist
- ◆ Name and purpose of the medicine
- ◆ What it looks like
- ◆ How much to give
- ◆ When and how to give it
- ◆ How often and for how long to give it

# What should I know?

- ◆ What to do if medicine is thrown up
- ◆ How it interacts with foods, other medicines, or other medical conditions
- ◆ Side effects that may occur
- ◆ Side effects to call the doctor about

# Measuring Medication

## *Liquid medications:*

- ◆ **USE** the following:
- ◆ Syringes and oral droppers
- ◆ Dosing spoons
- ◆ Medication Cups
- ◆ **DO NOT** use standard tableware tablespoons or teaspoons because they are usually not accurate.

# Liquid Medication

- ◆ Shake well immediately before giving to your child.
- ◆ Read the label on the container-for the exact amount to give
- ◆ Use medicine dropper, oral syringe, medicine cup or medicine spoon.
- ◆ Infants: Place in small amount of breast milk or formula.
  - ◆ **DO NOT** add medicine to the whole bottle.
- ◆ Give **the medicine first, before** the feeding.
- ◆ Squirt small amounts of the medicine into the side of the cheek, while infant is sucking on pacifier or nipple.

# Liquid Medication

- ◆ Children:
  - ◆ Squirt small amount of medicine in side of cheek.
  - ◆ Use medicine cup or medicine spoon.

# Pills & Capsules

## 💧 Pills and Capsules:

- 💧 For children **who cannot swallow** pills, check with the pharmacist whether it is okay to crush the tablet or open the capsule.
- 💧 If it is okay, you can do the following:
  - 💧 Tablets can be crushed
    - 💧 Between 2 spoons
    - 💧 Inside a plastic bag
    - 💧 In folded paper

# Capsules

- ◆ Capsules can be opened
- ◆ **Do not** crush the little beads.
- ◆ Mix the powder in a very small amount of soft food, such as pudding or applesauce.
- ◆ Make sure your child takes all of the mixture.

# Tips

- ◆ It is not always easy to give medications to children.
- ◆ Use a calm, firm approach.
- ◆ Be honest and sympathetic.
- ◆ Explain the need to take the medication.
- ◆ Praise a child for taking medicine.
- ◆ Incorporate taking medicine into a routine.

# Safety

- ◆ Avoid calling the medicine candy.
- ◆ Store all medicines in their original containers.
- ◆ Store medications as directed.
- ◆ Away from direct sunlight or heat.
- ◆ Refrigerate if need.

# Safety

- ◆ **Do not** store in humid places such as the bathroom.
- ◆ Always request childproof medicine bottles/containers.
- ◆ Keep them out of the reach of children.
- ◆ Always finish the prescribed course.
- ◆ Always give all doses prescribed. If the RX says 5 days, give the medicine for all 5 days.

# Safety

- ◆ Never give your child leftover medicine.
- ◆ Call your doctor/clinic if you think your child needs a new prescription.
- ◆ Never use one child's medicine for another child.
- ◆ Protect against POISONING
- ◆ Flush all leftover medicine down the toilet
- ◆ Teach child the meaning of the “skulls and crossbones”

# Safety

- ◆ **When to call for medical help:**
- ◆ For swelling, trouble breathing, seizure, or unconsciousness, call **911**
- ◆ For rash or other side effects, call the doctor/clinic or pharmacist. Do not stop giving the medicine without asking first.
- ◆ If too much or the wrong kind of medicine is taken, call Poison Control at 1-800-222-1222.

# Giving medicines to a child

- ◆ *Your child should be awake and alert when taking any medicine.*

# Community Resources

- ◆ Children and Adolescent Mental Health Division- Family Guidance Centers, Hawaii State Department of Health
- ◆ Hawaii Community Genetics
- ◆ Developmental Disabilities Division- Hawaii State Department of Health