

Service, Support and Success

The Direct Support Workers Newsletter

Medication, Education and Advocacy:

Useful Insights: Improving How People with Developmental Disabilities Use Medication



By: Yona Lunsky and Virginie Cobigo

A few opening questions

How many medications do you take each day? How did you decide to take them, and how do you know they work? How bad are the side effects, and what do you do to tolerate them?

One last question: What would happen if you were unable to ask yourself any of these questions or if no one helped you figure out the answers? Consider this story....

My brother had been on numerous medications for almost 10 years. He became very quiet, slowed down and sluggish. He also gained a lot of weight and didn't have the energy he used to have. Over those 10 years, we began to feel that this was just who he was and forgot about his old energetic self who was always on the go. However, he began to get upset with this sluggish self and slowly became more aggressive and began lashing out, always telling us he didn't feel well or wasn't happy. It was a long and painful process, but we eventually realized that he was likely overmedicated. Once this issue was cleared up, we saw a re-emergence of his old self. With the right balance of medication, he could be happy and energetic and also have his psychiatric issues under control.

—Francine (from *Atlas*, Chapter 6)

Medication use is very common for individuals with developmental disabilities. But medications can also lead to problems when you struggle with how to report whether a medication helps or not, or when others aren't alert to the impact of the side effects. In the story above, Francine and others started to forget that the person before them was not the person they knew and loved. And it was very frustrating for Francine's brother as well to not feel like himself. Fortunately, they had the patience, motivation, and clinical support to set things straight. But it does not always work out that way.

Medication training for staff has historically had a focus on "medication dispensing." Staff were taught about medication safety, where to keep medications, how to administer them, when to give them out, and how to document what occurred. But while medication safety is terribly important, it is not enough. We now know that when it comes to medication, a support worker needs to be:

- An advocate who can support those taking medications to be their own advocates in health care discussions,
- A communicator about the need for medication, and the effectiveness of medication,
- A teacher about what medications can do, how to take them safely, and how to monitor them, and
- A monitor who can keep on eye on the effects of medication, and report them to healthcare professionals.

What challenges do adults with developmental disabilities face when it comes to medication use?

Adults with developmental disabilities are at a higher risk for physical and mental health problems. As a result, they tend to get prescribed many different medications. But it's very difficult for people with developmental disabilities to identify and report side-effects from medication. Also, although medications aren't necessarily bad, taking too many, not enough, or not the right ones can lead to problems. Not being able to ask questions about the medications or not following instructions can also result in serious issues.

The Health Care Access Research and Developmental Disabilities (H-CARDD) Program studied medication use by 52,000 adults with developmental disabilities, who get their medication paid for by the Ontario Drug Benefit Program. Here are a few things they found:

- Nearly one in two adults takes two or more medications.
- One in five receives five or more medications at the same time.
- Older people, women, and those with diseases receive a lot of medication.
- Of all the medications given, antipsychotic medications are prescribed most often.
- One in five adults who take antipsychotic medication may take two at one time. This medication combination can put them at risk for very serious problems, even death.

What can staff do to help people with developmental disabilities manage their medication use?

Careful monitoring is essential. The treatment team should work with the person taking the medication and caregivers to identify the effects of each medication and figure out ways to monitor them objectively. The focus needs to be on observable behaviours.

There are many ways to minimize side-effects. These strategies include:

- Taking the medication in smaller doses spread over the day.
- Taking medication with appropriate food.
- Taking an additional medication to treat specific side-effects.
- Changing the medication.

Remember that some individuals with developmental disabilities might be hypersensitive to medications. A side-effect that may not feel like much to you could be intense for them. For

example, dizziness can be an annoyance for anyone, but if you already have problems walking steadily without medication, any additional dizziness could be very dangerous. Small adjustments in medication can make a significant difference for someone affected by side-effects.

What can staff do to monitor medication use?

Staff should make sure they know the name and dose of each drug and why it has been prescribed. Local pharmacies can print out this information. It is important to get all prescriptions filled from the same pharmacy. The pharmacist is always available to answer questions about any medication, as well as how different medications interact when taken at the same time. A medication for a physical problem might interact with a medication for a psychiatric issue. Those who prescribe medications need to know the complete list. That's why it is so important for staff to keep track of medications and to keep the family physician updated about all of the medications that are being prescribed.

When there are multiple doctors involved, each treating different problems, they may not know about other medications that are unrelated to the problem they're focused on. Have a list of medications for every medical appointment. One easy way to do this is to get an updated printout from the pharmacy.

Walk-in clinics can be convenient, but keep in mind that their staff also will not have a full picture of the medications being used. It is always better to see a physician who knows you best. If that can't happen, at least have up-to-date information available for walk-in appointments.

In an emergency, the staff at the hospital emergency department may be able to view the list of current medications covered through the person's drug benefits plan on the hospital computer. But they may not know that the person you support is part of a drug plan, so you should tell them that information. A hospital can also call your pharmacy to get that information in an emergency.

Staff can also help to monitor medication by:

- Ranking symptoms of the illnesses on a scale of one to 10 and reporting any improvement.
- Tracking behaviours in a journal to determine whether or not medication is working (for example, what happened when a certain dosage was changed?).
- Noting side-effects and discussing them with the treatment team.
- Checking with a doctor and/or pharmacist for drug interactions before new medications are given (prescription or over-the-counter).

The input of staff is very important when making changes to medication. Staff can help those taking medications to report on how the adjustment is going: are symptoms worse? Are side-effects better?

Staff can also help individuals prepare before a meeting with a health care provider, to give medication feedback.

Sometimes, staff may be the only people who can help the doctor decide if it is a good time to make changes to a medication regimen. If there are significant changes in a person's routine or living situation, it might not be the best time to monitor medication changes. After all, it might be impossible to know how much of the change is due to the life situation and how much is due to the medication.

In Conclusion

It takes a team-based approach to improve how individuals with developmental disabilities use medications. Staff are an important part of that team. Education for adults with developmental disabilities and their caregivers on the appropriate use of medications and on monitoring side-effects is important.

More Information

H-CARDD website www.hcardd.ca

LD Medication Guideline: Using Medication to Manage Behavioural Problems in Adults with Learning Disabilities (University of Birmingham)

<http://www.birmingham.ac.uk/research/activity/ld-medication-guide/index.aspx>

Project MED Educational Booklets and International Consensus Handbook (Nisonger Center)

- Philip Green

<http://nisonger.osu.edu/projectmed>

ATN/AIR-P Medication Decision Aid: for Families of children with ASD (Autism Treatment Network)

<http://www.autismspeaks.org/science/resources-programs/autism-treatment-network/tools-you-can-use/medication-guide>

Auditing Psychotropic Medication Therapy (Surrey Place Centre)

- <http://www.surreyplace.on.ca/Documents/Auditing%20Psychotropic%20Medication%20Therapy.pdf>

ANTICHOLINERGIC EFFECTS	
Side-Effect	Management Strategies
Dry mouth	<ul style="list-style-type: none"> • chewing sugarless gum or sucking on sugarless or sour candy (both dry mouth and excess sugar can increase the risk of tooth decay) • ensuring good mouth hygiene, including frequent brushing, flossing and use of mouthwashes • having regular dental checkups • using oral lubricants (e.g., MoiStir)
Dry eyes and/or blurred vision	<ul style="list-style-type: none"> • getting a prescription for eye drops
Constipation*	<ul style="list-style-type: none"> • increasing fluid intake (e.g., water, juice and other non-caf-feinated, non-alcoholic beverages) • increasing regular physical activity and exercise • increasing dietary fibre (e.g., bran, raw fruits and vegetables) • trying a bulk laxative (e.g., Metamucil, Prodiem) or stool soft-ener (e.g., Surfak, Colace) • avoiding regular use of stronger or stimulant laxatives (e.g., sennosides [Senokot], bisacodyl [Dulcolax])
Urinary retention	<ul style="list-style-type: none"> • if mild, patience and running water while attempting to urinate • if more severe, a prescription medication to help counteract this effect

CENTRAL NERVOUS SYSTEM EFFECTS

Side-Effect	Management Strategies
Drowsiness	<ul style="list-style-type: none"> • taking most of the dose, or the full dose if possible, at bedtime
Lack of muscle co-ordination or muscle weakness (ataxia)	<ul style="list-style-type: none"> • checking with a doctor since it may be due to too high a dose
Headache	<ul style="list-style-type: none"> • trying over-the-counter headache remedies such as acetaminophen (Tylenol), acetylsalicylic acid (Asprin) or ibuprofen (Advil)—but first asking a doctor or pharmacist to check for possible drug interactions • getting a prescription for a different medication if, with time, headaches don't go away

INCREASED ENERGY (ACTIVATION EFFECT)

Side-Effect	Management Strategies
Extrapyramidal effects (tremor, restlessness, muscle stiffness and spasms, difficulty walking)	<ul style="list-style-type: none"> • adjusting the dose (done by doctor) • getting a prescription for anti-Parkinsonian drugs (e.g., benzotropine [Cogentin])—but this medication must be monitored, as excessive doses may cause other side-effects such as disorientation, confusion and delirium) • taking propranolol, a prescription medication used to treat tremor or restlessness • taking a benzodiazepine (e.g., lorazepam [Ativan]) to treat restlessness

GASTROINTESTINAL EFFECTS	
Side-Effect	Management Strategies
Nausea	<ul style="list-style-type: none"> • taking medications with meals, having small snacks or drinking milk • not using antacids within two hours of taking the medication, as they may interfere with drug absorption
Diarrhea	<ul style="list-style-type: none"> • trying loperamide (Imodium) or attapulgite (Kaopectate) after checking with a doctor or pharmacist for any drug interactions • taking smaller doses throughout the day or—if the diarrhea is the result of taking lithium—using a slow-release preparation (sudden diarrhea may indicate lithium toxicity)

CARDIOVASCULAR EFFECTS	
Side-Effect	Management Strategies
Dizziness, fainting	<ul style="list-style-type: none"> • getting up slowly from a lying or sitting position and dangling feet • wearing support hose and doing calf exercises to reduce blood pooling in the calves • taking the drug in smaller, divided doses throughout the day
Rapid heartbeat	<ul style="list-style-type: none"> • reporting this side-effect to a doctor—however, this is usually not a serious problem
High blood pressure	<ul style="list-style-type: none"> • speaking to a doctor about reducing the dose, changing medications or adding a high blood pressure medication

OTHER	
Side-Effect	Management Strategies
Weight effects	<ul style="list-style-type: none"> • reducing carbohydrate and sugar intake and consulting a dietician, if possible • increasing physical activity and exercise
Sexual side-effects*	<ul style="list-style-type: none"> • reporting these side-effects to a doctor, as all treatments for this side-effect involve prescription medications • trying a different drug, if these side-effects don't go away over time
Difficulty regulating extreme changes in temperature (altered thermo-regulation)**	<ul style="list-style-type: none"> • spending only a short time in saunas or out in the sun on hot humid days due to increased risk of sunstroke • drinking plenty of fluids and staying in the shade as much as possible • wearing loose-fitting clothing and a wide-brimmed hat • avoiding overexposure on freezing days due to increased risk of hypothermia
Photosensitivity	<ul style="list-style-type: none"> • avoiding prolonged sun exposure • wearing loose-fitting clothing and a wide-brimmed hat • always using sunscreen with an SPF of 15 or higher
Excessive sweating	<ul style="list-style-type: none"> • using talcum powder and a stronger antiperspirant (e.g., Drysol) for greater comfort • speaking to a doctor about reducing the dose • speaking to a doctor about adding another medication if a severe case

*The impact of these side-effects is not limited to people engaging in sexual relations with others. For example, some men can experience serious distress because a medication they take causes difficulties reaching a climax while masturbating.

**It is important to watch a person with a disability who cannot report their own temperature. It becomes the caregiver's role to keep them comfortable, hydrated and dressed appropriately.

About the Authors

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