

Medication, Education and Advocacy:

Useful Insights: Improving How People with Autism Spectrum Disorder and other Developmental Disabilities Use Medication

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When a physician prescribes a patient medication, they have a conversation with one another about how much medication to take each day, the different ways to take the prescription, how the patient will know the medication is working, and any possible side effects caused by the medication. This is an important ongoing dialogue that helps to keep the patient informed, but what happens when a patient is unable to have a conversation or ask questions like this with their doctor? What happens to patients who need assistance with figuring out the answers?

Francine's 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 reemergence of his old self. With the right balance of medication, he could be happy and energetic and also have his psychiatric issues under control.

Taken from The Atlas on the Primary Care of Adults with Developmental Disabilities, chapter 6.

Medication use is very common for people with a developmental disability like Autism Spectrum Disorder (ASD). But medications can also lead to problems for someone who might 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 notice 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. Family and caregivers can play a supportive role in monitoring their loved ones use of medication.

Medication training has historically had a focus on “medication dispensing.” This is similar to receiving a prescription from the drugstore with an accompanying piece of information about the prescribed medication, including safety, where to keep medication, how to administer it, when to give it, and how to keep track. While medication safety is terribly important, it is not enough to support people on the spectrum who require assistance in taking medication. We now know that when it comes to medication, a family member or a caregiver 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 an eye on the effects of medication, and report them to healthcare professionals.

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

Adults with ASD and other 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 on the spectrum 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, including those with ASD, 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 families and caregivers do to help people with ASD manage their medication?

Careful monitoring is essential. The families and caregivers should work closely with the person taking the medication and their treatment team to identify the effects of each medication and figure out ways to monitor them objectively. The focus needs to be on observable behaviours, similar to how Francine had observed her brother's weight gain, his lethargy and aggression. When a family focuses on observable shifts in behavior in their loved ones, they are more likely to minimize side-effects of prescribed medications.

A family member can make a prescribing physician aware of any changes in behaviour in their loved ones, and in response, a physician can find 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 sideeffects.
- Changing the medication.

Remember that some people with ASD and other developmental disabilities might be hypersensitive to medications. 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 a family member do to monitor medication use?

Many families do not tend to receive education around medication use, with the exception of explanations about the medications and their side effects which they receive from their pharmacist. Family members who are advocating and supporting a loved one on medication 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 family members and caregivers 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. It is recommended that family members have a list of medications for every medical appointment. One easy way to do this is to get an updated printout from the pharmacy. While walk-in clinics can be convenient, it is important to remember that their staff also will not have a full picture of the medications being used. It is always better to see a physician who has a history of a loved one. 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 being supported is part of a drug plan, so families should be prepared to share that information. A hospital can also call a pharmacy to get that information in an emergency. Family members can 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 from families or caregivers is very important when making changes to medication and they can help those taking medications to report on how the adjustment is going: are symptoms worse? Are sideeffects better? Families can also help a loved one with ASD prepare before a meeting with a health care provider, to give medication feedback.

Sometimes, a family member may be the only person 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 people with ASD and other developmental disabilities use medications. Family members and caregivers are an important part of that

team. Education for adults with ASD 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-medicationguide/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/resourcesprograms/autism-treatment-network/tools-you-canuse/medication-guide>

Auditing Psychotropic Medication Therapy (Surrey Place Centre) <http://www.surreyplace.on.ca/Documents/Auditing%20Psychotropic%20Medication%20Therapy.pdf>

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