

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:

having to schedule my life with added dependents and creating a new dual-routine (for

babies and I...oh yes, and adding my partner to this routine-mix). Before my babies came along, I was used to having a well organized and strict routine. I have now come to realize that this is not always possible with little ones in the picture. Although my family and I try our best to follow consistent schedules, this is not always practical. Therefore we have learned to adjust our schedules and be flexible, as situations will often arise that cannot be anticipated, controlled or planned for ahead of time.

On an emotional level, I did worry greatly about bonding with my children. My first time around, I thought my child wouldn't bond with me as much because I was returning to a full-time work schedule. After having a second child, I now know this is untrue. I am now aware that my kids know who their mama is and love me dearly. Since my latest return to work, one of the most amazing feelings I have experienced has been at the end of my workday, when I walk in to see two little bodies running rapidly towards me, yelling "Mamaaaaaaa"! With their arms open wide, we crash into each other, and with a big tight hug, a greeting happens. Best feeling ever! I presently have an awareness of the important example I am setting for my children – demonstrating a positive role-model, setting an example of hard work and dedication, as well as allowing them the opportunity to strive towards their own dreams as well."

Chanelle – proud mother of a three year old and a one year old

As a result of the collaboration of our experiences, we hope the following tips work well for you, just as they have for us. The succeeding list of strategies has been designed to help you navigate your emotional journey back to work and to establish work-life balance:

Making Connections

During your time on leave, you have likely made connections with other people through activities such as, baby groups, drop-in centres, neighbourhood walks and time with friends and family members. Keeping these relationships alive can help remind you of the positive experiences and personal accomplishments during your first year as a parent. There are wonderful family resources available through 'Public Libraries', 'Early Years Centres' and 'Public Health' in many local cities. These resources offer workshops, drop-in play groups and coaching on different parenting topics and developmental stages, and most are offered at no cost to families.

Once you return to work, you will begin to connect or reconnect with your supervisor and colleagues. It is really important to meet with your supervisor and coworkers as soon as possible after you return to your job role. This will give you a chance to discuss any changes that have happened since you've been away and will offer you time to get reacquainted with your work team. Make time to check in regularly with your coworkers and immediate work team (e.g., the other direct-care support within the day program or home you support). Your support team will also be an important outlet during the times you feel you need extra support or creative ways to problem solve. Connections to others in both your personal and professional circles will help you balance and adjust your new priorities in each area of your life and will be a key part in helping you to feel emotionally grounded.

Staying Present

To get the most out of your family and work life balance, it is important to focus on being present as

much as possible. Make an active commitment each day to leave your work at the door as soon as you arrive home at the end of your shift. This might mean finding a way to visually cue the transition from support worker to parent. For example, changing your outfit as soon as you arrive home from your shift for the day/evening. During your time with your family and your children, do your best to be actively engaged in what they are doing. Make the moments count and focus on quality over quantity.

Being present and 'in the moment' at work will also help you get the most out of your role in providing support to the individuals in your care. While it is tempting to dwell on the baby and focus on wondering how they are doing while you are at work, this will likely lead to more anxiety and cause you to become distracted. Try using techniques such as 'self talk' to remind yourself to refocus on your work and the people that you support. Find a specific task that you are working on with an individual to help you get back on track. For example, "(individuals' name) needs my support in learning how to use the public transit system".

Embracing your identities

Let's face it; you have added a very important new piece to your identity since becoming a new parent, that being the role of 'mommy' or 'daddy.' This might be in addition to your other roles of partner, wife, husband, sister, brother, son, daughter, employee, uncle, aunt, friend, and the list continues... With all of these different titles, it's no wonder you feel a push and pull between so many roles and different expectations. As you gain this new identity, it is also very important to remember that you are also YOU!!!! Try to do something each week that speaks to your unique qualities or interests as an individual. Think back to what you enjoyed doing before you became a parent and focus on trying your best to incorporate this back into your regular routine. Some ideas might be going back to a hobby that you enjoyed in the past or making time to connect with a friend that knows you outside of your support worker or parent role. This way they can help you celebrate YOU as the person that they have come to know and appreciate.

Doing things that make you feel good and recharged

As a full-time support worker, in both your personal and work roles, you are likely the last person to worry about your own emotional energy or well being. As long as those you love and care for are healthy and o.k., then you can feel confident and good about the 'juggle' in which you are engaged. It is so important to remember that you can only give out as much energy as you have. Therefore, if you become too tired or burnt out, you will find it difficult to continue to give your best to your children and the individuals you support. Make time to refuel and recharge between your parent and work priorities. Make a point of scheduling 'ME TIME' on a regular basis and avoid cancelling this when others ask of your limited time. It is much easier to gracefully decline when you have your schedule outlined in your agenda or family/work calendar ahead of time then trying to come up with a reason to say 'no' in the moment or on the spot.

Asking for Help

There will be times that you as a parent and support worker will need the support and help of others. Be realistic about what you are able to accomplish in each role. Avoid taking on too much right at the beginning of the transition. Remember your schedule has changed considerably and you will need time to adjust and figure out how you can fit in your new priorities. Do not be afraid to ask for

help – family members, friends or trustworthy neighbours, before the ‘overwhelmed’ feeling strikes. They can even help to feed child(ren), babysit, bring a meal, or simply share time and socialize.

Create a to-do list

Having a list that outlines everything needed to be done that day can be very helpful. However, if you find you are frequently rewriting your “to-do” list throughout the day (as things do tend to pop up unexpectedly i.e., an illness), then it may be helpful to look at your list as a triage method. Review your list on a day-to-day basis and identify items that are of higher priority (what has to be done right away, followed by what can wait). So, yes, triage your life!

Quality vs Quantity

There will be times when you feel guilty. When you feel overwhelmed with emotion because of the overpowering guilt due to feelings and thoughts of not being able to spend enough time with your child(ren). This is quite common amongst working parents. Just remember that quality time is key to bonding. Spending 1:1 time together, engaging in activities together, turning off all electronics/technology for as long as needed to ensure a higher level of interpersonal engagement is occurring. For some families, dedicating a day free of technology works wonders i.e. Tech-free Tuesdays! It also helps me if I leave my phone in the car, far enough away so I do not feel tempted to check or send any texts or emails. This increases both the quality time spent together and being present in the moment. Also, finding a program to attend together will ensure you are focused only on your child(ren) (check your local recreational centre for programming).

Partner time

Setting aside time to be with your partner and focus on your relationship becomes even more important after having a baby. Once kids enter the picture it might feel like it is impossible to think about anything else other than the needs of your child(ren). However, feeling connected to your partner can only help you feel supported when you are juggling the needs of your family and your work. Set aside time in your schedule for partner time on a regular basis. Consider planning ‘date nights’ on a weekly basis. Time with your partner does not need to involve money or going out somewhere, but could be as simple as watching a movie at home with a bowl of popcorn. The key is protecting time to focus only on each other without distractions and appreciating each other outside of the parent roles. A lot of the time, the simple thoughtful gestures have a big impact! For example, calling or texting your partner on lunch or break to say you appreciate, miss or are just checking in with him/her about their day.

Phone Apps

Finding useful Apps to help you navigate your day can be quite helpful. The following are common Apps used with android or iPhone:

- Astrid Task (free, android): helps create a to-do list and imports work and personal tasks, allowing for reminders for completion. This can also be synced with another’s phone i.e., family members and/or work teams.

- Evernote (free, android or iPhone): saves texts, notes, voice recordings to an online account and access can be made from any device.
- Mint.com: helps manage finances and great for budgeting and balancing across accounts.

Establishing a healthy work-life balance can be quite complex, however, it is not impossible. It helps to gain self-awareness and to remain mindful of what works for you and your family. This will allow for further flexibility within one's self, and to be able to navigate between home and work life, which in turn will help you to do your best in both roles.

A First Day Back Story

It was my first day back to work. To say I was nervous would be an understatement! My stomach was in knots as I prepared myself that morning. I felt dizzy from the hustle and bustle of rushing to get myself and my family ready to get on our way.

I made it to work with just enough time to find parking and go inside the building. Although I did my best to focus on getting reacquainted with my coworkers and the individuals I support, I found myself thinking and wondering about how my little one was doing and adjusting to their new caregiver and day care setting. I even took a few minutes to check in with the caregiver on the lunch break. The caregiver reassured me that my son was just fine and was enjoying looking at and exploring all the new toys and play areas.

When the end of the day finally arrived, I was overwhelmed with nervous anticipation. The drive to the day care felt like the longest drive I had ever experienced! My mind raced to thoughts and visions of my baby. I worried that he would be scared, sitting by himself, or crying and waiting anxiously for me to come back for him. After parking the car, I ran the two blocks to the day care building. As I entered the day care, I spotted my son right away from across the play room. When he saw me, he immediately smiled and crawled towards me quickly from the other side of the room. After we shared a quick cuddle, he crawled away again and went over to a large play house where he joined two playmates inside. I walked over and watched them play alongside each other for a few minutes. It was very clear that my son was enjoying watching the older kids and learning new ways to play with toys. I laughed to myself as I thought about how comfortable and at ease he looked in handling this new setting and transition. I sighed happily realizing that we would both be O.K. after all!

“It is all about quality of life and finding a happy balance between work, friends and family.”
- Philip Green

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