Winter 2023
ISSUE #13

3.21
Canada's
Down Syndrome
Magazine

WE LOVE OUR CAREGIVERS:
A Self-Advocate Q&A

COMING TO TERMS:
Down Syndrome and Grief

Caring for the Caregiver

Unhelpful Parenting Thought Patterns

Plus: ***Caregivers share their joys and challenges, and tell us how to take the stress out of the holidays***

3.21 Canada's Down Syndrome Magazine is a joint publication of

Canadian Down Syndrome Society | Société canadienne de la trisomie 21

Down Syndrome Resource Foundation

In the event of an airplane emergency, travelers are instructed to secure their own masks before helping others with theirs. It may go against every parental instinct, but you can't help your child (or anyone else) if you pass out from oxygen deprivation.

The same goes for caring for a loved one with a disability. Caregivers naturally – and, often, heroically – put the needs of their loved ones with Down syndrome before their own. While it's both understandable and admirable, it's ultimately unsustainable. For the sake of both the caregiver and the one receiving care, it is essential that those in supportive roles ensure their own emotional and physical needs are met.

Whether you're a parent, sibling, friend, or paid support worker, this issue of 3.21 Magazine is for you. Within these pages, you'll find suggestions for coping with the grief associated with a Down syndrome diagnosis, strategies for avoiding common parenting thought traps, and wisdom from other caregivers who share their own self-care strategies. Plus, with this being our winter issue, you'll find some tips for making the holiday season an enjoyable and relaxing time for all members of the family. We hope you'll take some time to replenish yourself before the busyness of the new year begins.

We would love to hear from you! Drop us a line and share your article ideas at **321DSMagazine@gmail.com**.

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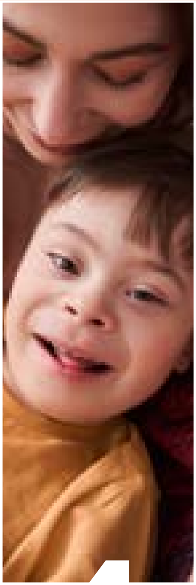

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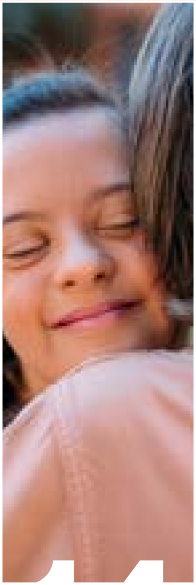

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UNHELPFUL PARENTING THOUGHT PATTERNS

AVOIDING PERILOUS THOUGHT TRAPS

By Dr. Susan Fawcett, with Glen Hoos

PERCEPTION IS REALITY, OR SO THEY SAY.

We're not exactly sure who 'they' are, but they make an important point. The way in which we perceive our circumstances shapes our response to those circumstances. Our response, in turn, shifts the circumstances – for better or worse. This creates a new reality... leading to new perceptions... and new responses... and around it goes.

Deep thoughts, but a simple principle: how we think really matters. So, it's worth thinking about how we think.

All of us have thought patterns: some healthy, some unhealthy. Those thought patterns inform our self-talk, an internal monologue running through our mind that helps us make sense of what's happening in our life. Positive self-talk helps us see the circumstances of our life in the best possible light and think rationally and productively about problems as they present themselves. Negative self-talk skews how we perceive our circumstances and sabotages our ability to effectively respond to challenges.

Caring for a loved one with Down syndrome presents all kinds of opportunities for unhealthy thought patterns. Parents, in particular, rarely receive any specialized training before welcoming a person with a developmental disability into their family. Their journey takes them down paths and around corners they never could have imagined, much less prepare for. This opens the door wide to self-doubt and other thought traps that negatively impact parental mental health.

Being the best version of ourselves – and the caregiver our loved one needs – starts with getting our thinking right.

PROBLEMATIC THOUGHT PATTERNS

The first step in healthy thinking is to identify problematic thought patterns that may be at work within us. Before looking at specific negative thoughts that are common to parents, here are some of the most common "thinking traps" that can impact us in every area of life.

ALL OR NOTHING (BLACK AND WHITE) THINKING: Taking complex issues and reducing them to simplified, either/or scenarios. For example, "If I'm not perfect, I have failed;" "Either do it right, or don't do it at all."

MENTAL FILTER: Only paying attention to certain types of evidence; noticing our failures but not seeing our successes.

OVER-GENERALIZING: Being overly broad in the conclusions we draw. For example, "I always do that;" "Everything is terrible, nothing good ever happens."

DISQUALIFYING THE POSITIVE: Similar to the mental filter, discounting the good things that have happened and accentuating the negative.

JUMPING TO CONCLUSIONS: Mind-reading (assuming you know what other people are thinking) and fortune-telling (predicting the future based on limited evidence from the present). Mind-reading is a particular favourite amongst married couples!

EMOTIONAL REASONING: Assuming that because we think something, it must be true. For example, "I feel embarrassed so I must have made a huge mistake."

MAGNIFICATION AND MINIMIZATION: Blowing things out of proportion (catastrophizing) or inappropriately shrinking something to make it seem less important. For example: "My child is going into kindergarten and still isn't potty trained. What if he never becomes potty trained?"

SHOULD AND MUST: Using critical words like "should," "must," or "ought" can make us feel guilty, or like we've already failed.

If you recognize yourself in any of these unhealthy patterns, don't be alarmed. We all fall into many or all of these thought traps at one time or another. The key is to recognize it and not let it dominate our perspective.

UNHELPFUL PARENTING THOUGHTS

The general thinking traps listed above manifest themselves in specific damaging thoughts in different realms of life. Some common themes include:

- How the parent sees herself or himself as a parent
- How the parent thinks others see her as a parent
- How the parent thinks others view her child
- How the parent sees her child's ability to control his behaviour
- How the parent views problem situations
- Who should be responsible for problem situations
- How the parent views the future

To get a sense of how these themes play out in everyday life, how many of these negative thoughts are familiar to you?

"Everyone is staring at us."

"I can't handle this."

"It's my fault my child is behaving badly."

"They must think I'm a terrible parent."

"I should be doing more for her."

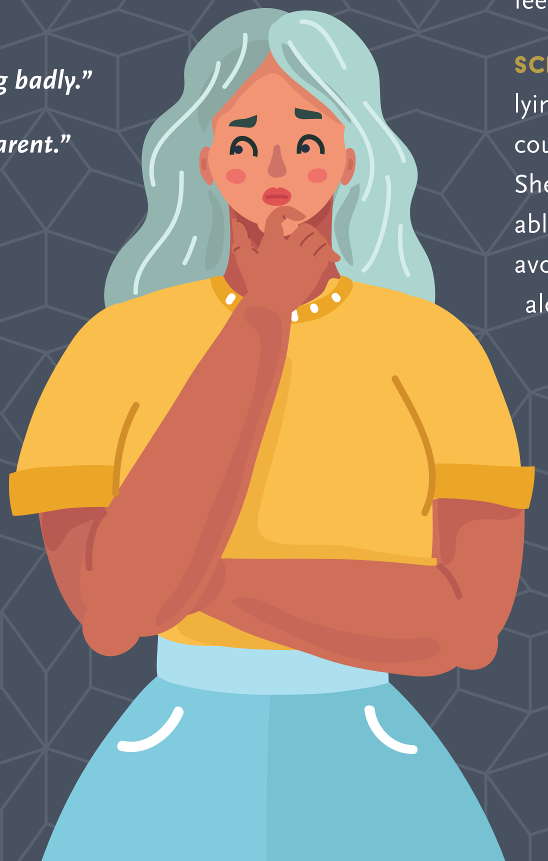
"Things are just getting worse."

"I should be more patient."

"I can't help my child."

"My child would read better if I would practice with him more."

"My child will always be dependent on me."



The way thought patterns impact emotions and behaviour (and vice versa) is explained by a framework known as the Cognitive Behaviour Therapy Triad. Consider the following scenarios, and how the thought pattern impacts the outcome.

SCENARIO 1: A father has been given a great deal of reading and speech therapy homework to do with his daughter. As he leaves the therapist's office, he thinks, "We'll never get this all done. It's my fault she's not improving. I should be doing so much more for her." He feels inadequate, sad, and guilty, and now these negative thoughts are connected to helping his daughter with her homework. We all tend to avoid uncomfortable situations, so these emotions cause him to avoid doing the work with her, leading to more feelings of failure, and so on.

SCENARIO 2: A mom is at the store with her son. He's lying on the floor screaming because she told him he couldn't buy a toy. She thinks everyone is staring at them. She is embarrassed and feels angry at herself for not being able to keep her child under control. She decides to begin avoiding taking her son out in public and do her shopping alone in the future.

How might these scenarios change if the parents shifted their thought patterns? Imagine if the father focused on his daughter's recent successes and the role he had played in helping her in those achievements. Or what if the mother recognized that she can't control her son's behaviour, and other kids have temper tantrums in stores, too? A change in perspective may not solve the immediate problem, but it can certainly put us on a better path.

CULTIVATING HELPFUL THOUGHTS

Staying positive in the face of significant challenges is undoubtedly easier said than done. We do have the tendency as human beings to focus on the negative. It takes intentionality and practice to accentuate the positive.

It begins with the most basic step: simply becoming aware of the fact that you are having either helpful or unhelpful thoughts. Next time you notice a shift downwards in your mood or an uptick in your anxiety, ask yourself: "What was I thinking about just now?" Then, take on the role of a detective and put your own thoughts on trial. Ask yourself questions like: Is this thought realistic? Is it true? Am I basing my thoughts on facts or feelings? What is the evidence for this thought, and could I be misinterpreting it? Am I viewing the situation as black and white, when really it's more complicated? Am I having this thought out of habit, or do facts support it?

These are clarifying questions. They reveal whether you are thinking in healthy, helpful ways – or not. And if you recognize that you're not, you can begin to reframe the situation.

Reframing involves taking a different, more positive perspective on an unhelpful thought. For example, rather than perceiving yourself as weak, you can reframe it and remind yourself that you are a gentle and calming presence for your daughter. Instead of beating yourself up for being impatient, you might say something like, "I'm getting better at being patient. I'm working on it. I'm more patient than I used to be."

Here are some more examples of reframing some of the common negative thoughts we discussed earlier:

UNHELPFUL	HELPFUL
“I should be doing more for her.”	“I am doing the best I can under the circumstances.” “We have already accomplished a lot today.”
“I can’t control his behaviour.”	“I am trying hard.” “He can now walk to school calmly.”
“It’s my fault my child is behaving badly.”	“She behaves this way for my wife and her teachers, too; it’s not just me.”
“Things are just getting worse.”	“She is able to say more words than before.” “Things are tough right now. Tomorrow might be better.”
“I can’t help my child.”	“It was me who taught our son how to zip up his coat!”
“I can’t handle this right now.”	“It’s tough, but I have done this before and I can do it again.”

Returning to the scenario of the child throwing a fit at the store, instead of thinking, “Oh my gosh, everyone’s staring at us,” the mom could take a deep breath and remind herself, “My son isn’t the only kid who does this. I can ride this out. I’ve done it before, and I can do it again.”

Now, I’m not going pretend that she’s not still going to be a little embarrassed by the situation. But she might have just a little less embarrassment; she might feel a little calmer and more confident, and – MAYBE – she may even be able to see the humour in the situation. Reframing the situation allows us to step back and see it in a different light, and that’s often where we find solutions.

Another useful strategy to consider is affirmation: becoming your own cheerleader. We all do better with encouragement, and it’s most powerful when it comes from ourselves, because we are often our own toughest critic.

Affirmation is about finding ways to boost yourself up and increase your confidence. It’s a powerful way to start your day: strike a superhero pose in the mirror, and tell yourself, out loud, things that make you feel strong. You may choose to focus on specific attributes of your parenting style and what you are good at, or things you have recently accomplished with your child. Or it might be something more general. Here are some examples of positive affirmations that you can try:

> ***“I am a gentle, but firm, parent.”***
>
> ***“I am exactly what my child needs.”***
>
> ***“I am a confident mother.”***
>
> ***“I am learning and I’ll do better next time.”***
>
> ***“I’ve got this.”***

And you know what? You’ve got this. You really do. You are doing an amazing job in a difficult situation. Don’t ever let yourself forget it.

RESOURCES:

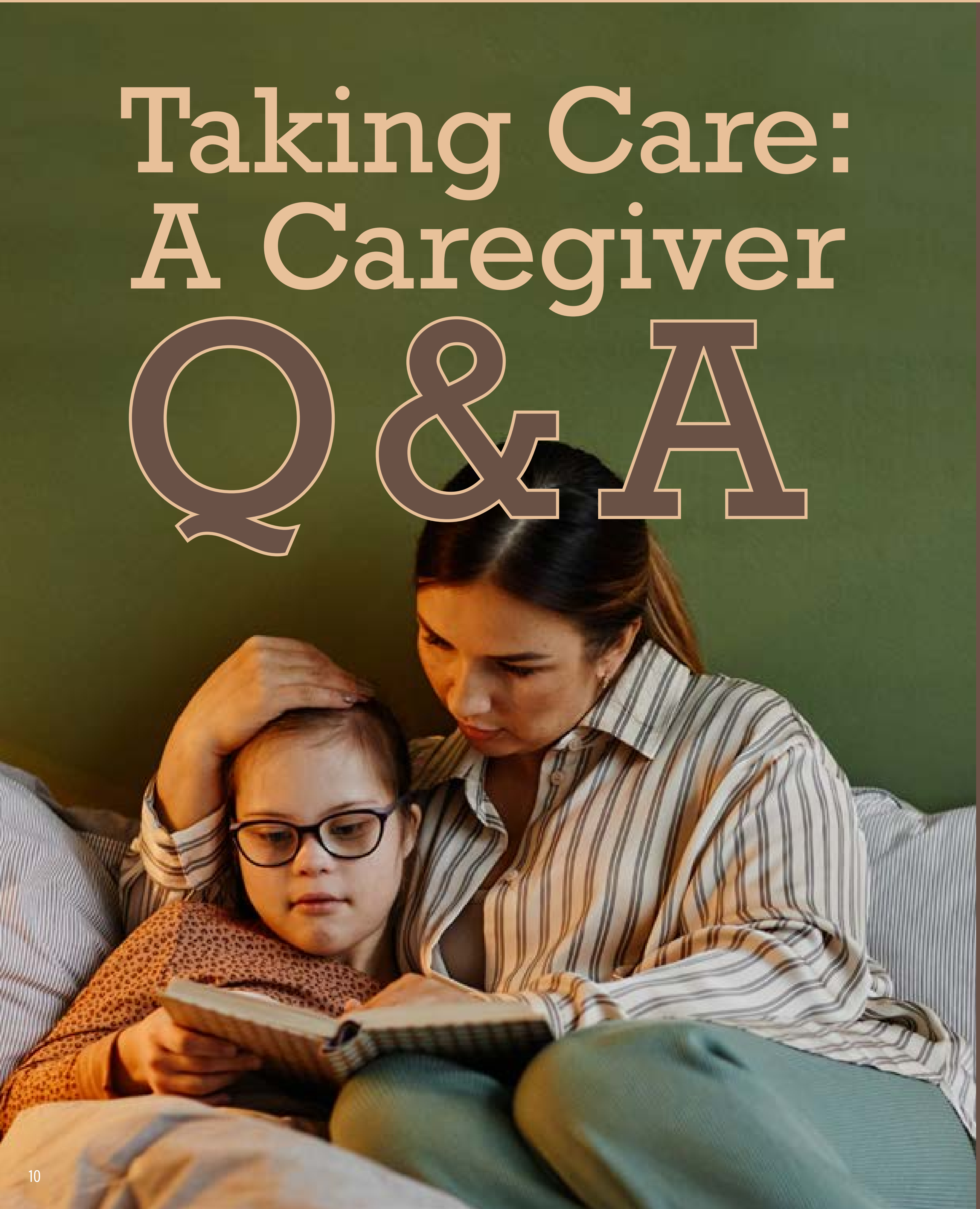
WEBSITES:

- **Parenting Special Needs Magazine**
- **Anxiety BC**

BOOKS:

- “Helping Parents with Challenging Children: Positive Family Intervention” – Mark Durand & Meme Hieneman
- “Get Out of Your Mind and Into Your Life: The New Acceptance and Commitment Therapy” – Stephen Hayes
- “CBT Basics & Beyond” – Judith Beck

Taking Care: A Caregiver Q&A



Sue, cares for Aaron, age 19

What are the biggest joys of being a caregiver?

My biggest joy as a caregiver is knowing that the real reason all of us are here on this Earth – not to make and spend money – is to look after each other as human beings.

What challenges do you face as a caregiver?

My challenges do not come with being a mother of three (now adult) children, including our youngest son Aaron who is 19 and has Down syndrome. My biggest challenges are with systems and society.

I had to quit my job when Aaron was 13 because it was not a family-friendly workplace and there is no youth childcare available in our province. I'm not supported financially at all as a caregiver; meanwhile, while our family feels a lot of pressure to make money to supplement Aaron's (inadequate) disability payments from the government.

There is little peer support for us caregivers who have adult children. We are pretty much on our own to build communities.

How do you take care of yourself?

I see my own mental health therapist once a month, which helps me a lot.

How can others (family, friends, employers, and other members of your loved one's support team) best support you in your caregiving?

I find that friends who do not have loved ones with disabilities say things like, "Oh well, all teenagers are hard,' and do not understand the extra complexity that comes with dealing with systems and having a kid with disabilities. Similarly, not all extended family is understanding. I subscribe to the 'love the ones you are with' philosophy. My biggest support comes from my husband and our other adult children. I am also grateful to the DSRF staff who do not give up on our loved ones and offer a safe and understanding space for families.

Stephanie, cares for Monika, age 14

What are the biggest joys of being a caregiver?

Monika is a beautiful, loving, and kind daughter. Just like any parent with a child, we strive to see our children be happy and succeed. Monika is a delight to be with and shares much joy and love within our family. It has been wonderful to see Monika blossom over the years into the confident and capable young lady she is today. We are excited to see what the future will continue to hold for her.

What challenges do you face as a caregiver?

Just like parenting any child, there are always struggles and challenges. Monika is very much a typical teenager, who sometimes needs a little extra encouragement to do certain things. However, I am honestly very grateful that Monika is quite independent and responsible. She lives a very inclusive life and has many friends from school and the neighbourhood.

How do you take care of yourself?

Like most mothers, I need to carve out time for myself to stay healthy. I like to run, bike, and play tennis to recharge and relieve stress. We try to go on family walks where we talk about our day. We try to be positive as well, which really helps in challenging times.

How can others (family, friends, employers, and other members of your loved one's support team) best support you in your caregiving?

I am very fortunate to have an amazing family and many wonderful friends, as well as fabulous teachers and therapists. They say it takes a village to raise a child; in this case, we are all in it together. I am very thankful to everyone for being a part of Monika's great foundation and helping raise her to be the great girl that she is.

Christie, cares for Becca, age 18

What are the biggest joys of being a caregiver?

One of the best parts of being a caregiver is the thousand ways she makes me laugh. Everyday I'm amazed by how hilarious or cute or loveable she is. That complete honesty and lack of self consciousness gives her a perspective that is so refreshing and a unique wisdom.

What challenges do you face as a caregiver?

I am always exhausted. Between therapies and appointments and dealing with problem behaviours, we rarely get a break. It can be isolating, both for her and our whole family, to live life with a different set of abilities and limitations than most. We are different and that is not bad, but it is frequently misunderstood and often lonely. The worst part for me is handling health problems, which range from minor annoyance to life-threatening and terrifying.

How do you take care of yourself?

I take a hot bath most nights. My husband and I take turns having a few hours to ourselves. We also go on a date every week. We use almost all our funding on respite. I see a great therapist.

How can others (family, friends, employers, and other members of your loved one's support team) best support you in your caregiving?

Give me a break - even if it's a few minutes so I can take a breath. If you are confused, worried, or unsure about something my kid is doing, ask me about it. Enjoy my child for who she is; that makes both of us feel cared for.

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Coming to Terms:
Down Syndrome and Grief

An Interview with Samantha French

The LowDOWN: A Down Syndrome Podcast recently welcomed Samantha French to discuss grief and Down syndrome. Samantha is a clinical family counselor who specializes in children with neurodiversities. She has worked with the Lumara Grief and Bereavement Care Society since 2013, attending and facilitating annual bereavement camps. Samantha is also an advocate for her twin brother, who has a developmental disability. This article is a lightly edited transcript of a portion of The LowDOWN Podcast episode, produced by the Down Syndrome Resource Foundation. The full conversation can be found at DSRF.org/podcast.

Trigger Warning:
This interview touches on some very difficult issues. Grief and loss can be triggering for everybody. Be gentle with yourself and, if necessary, give yourself permission to stop reading and return to it at an appropriate time.

The LowDOWN: Can we begin by defining what grief is, and how it might be experienced by a person or a family?

Samantha French: Grief is a heavy topic, but it's one that is common to every human being. The reality is, every one of us will experience grief in some way, shape, or form – probably multiple times throughout our life. And yet, a lot of people are very afraid of grief.

Grief is essentially our response to the loss of something. It may be a person, it may be a job, it may be an ideal, or something that you had in your mind that was going to happen, and then it didn't. It's anything that you had a very strong connection to that has now ended.

Because grief encompasses many different experiences, it takes many different shapes. Everyone grieves differently. And, though a lot of people think that grief happens all in your mind, what we know about grief and loss is that we experience it with our whole body. Grief has physiological, emotional, cognitive, and behavioural impacts.

LD: And grief can be recurring, right? You may feel like you're absolutely done dealing with it, but then it comes back out of nowhere.

SF: One of the things we say is that grief is a lifelong process, especially when you've lost a person who's very close or experienced a major trauma. Throughout your life, when memories of that person or situation pop up from time to time, it's going to be a reminder and it's going to re-trigger a little bit of that loss. Depending on how you've dealt with it and the process you've gone through, it's not always going to look the same throughout your life. And that's one thing people are really worried about in that initial phase of grief where it feels really heavy and really hard: they're worried that it's going feel like that for the rest of their life. The good news is, even though grief is a lifelong process and something that we always carry with us, it won't be so acute forever, if we deal with it in a healthy way.

LD: You mentioned at the outset that grief isn't only related to death. This is a complex and sensitive topic, but we have found that parents almost universally experience a form of grief when they receive the initial diagnosis of their child with Down syndrome. What might grief be like in that instance?

SF: So, this is a situation where you had an expected life for yourself, and for your child, and then you suddenly learn that your future and your child's future is going to look different than you thought. It's not that you stop having a life for yourself or your child, it's just going to be a different life than you imagined.

People respond to this kind of news in different ways. It can often be something where we see a lot of anger. There's definitely some sadness with it. Sometimes we see significant bodily reactions in those first moments, with a little bit of withdrawing or numbness.

As people move through the stages of grief, they usually move beyond the anger and sadness, into a place of advocacy. They turn it around and realize, "I have some control here in what I can do." They discover resources and supports that help them through that process, give them a clearer idea of what to expect, and what they can do to help their child have the best life possible. But that takes time, and there will still be moments when they may slip back into sadness or even anger.

LD: It sounds like a sort of anticipatory grief, as though there is a mental highlight reel of what we're going to do as a family. We can picture it and it's going to be awesome;

it's going to look like *this*. But then that gets taken away with a diagnosis. Perhaps that's why the diagnosis conversation stays with people for a very long time, if not forever: because that is the moment when the plan exits the room.

SF: Absolutely. You're starting over again. You've lost your footing, and now you've got to figure out this new terrain.

And yet that terrain has changed dramatically over time. Back in the day when you received a diagnosis, often the parent had to come to grips with a doctor basically saying, "You've got to get this child into an institution, and their life expectancy isn't going to be that long." That created a sense of anticipatory loss: the child has just been born and you're already dreading the day they are going to die.

Thankfully, that is not the case anymore. Now what we're seeing is anticipatory grief from caregivers. Their child is going to have a significantly better life, which is obviously fantastic, but it brings additional complexities and worries. Parents quickly start to wonder, "What's going to happen to this child when I am gone?" People are getting a diagnosis and immediately thinking 30 years, 50 years, 60 years ahead when usually we only think five to ten years into the future.

I'm all for planning ahead. Providing parents with lots of information up front is helpful, especially when the child is going to have developmental milestones that are a little bit different than a neurotypical child. But that doesn't mean it's not going to hurt. It's not a substitute for the grieving process. And I think that that's a misconception with anticipatory grief: if you just prepare enough, if you research enough, you can keep the feelings of grief at bay. That's not how it works.

LD: That's a great segue into coping mechanisms. We've all heard terms like avoidance, deflection, minimization. Can you walk us through a few of those?

SF: The wonderful seven stages of grief? Yes, let's talk about that.

When it comes to processing grief, we're still learning. We started out with a very rigid model: you're going to go through these steps in this order. But we quickly came to realize that this isn't the case, actually: it doesn't reflect how grief works in the real world.

It is common to experience certain emotions as part of the journey (sadness, anger, bargaining), and ultimately move into an acknowledgement and acceptance phase. But it doesn't often go in that order, and it doesn't often stay in that order. It's not linear.

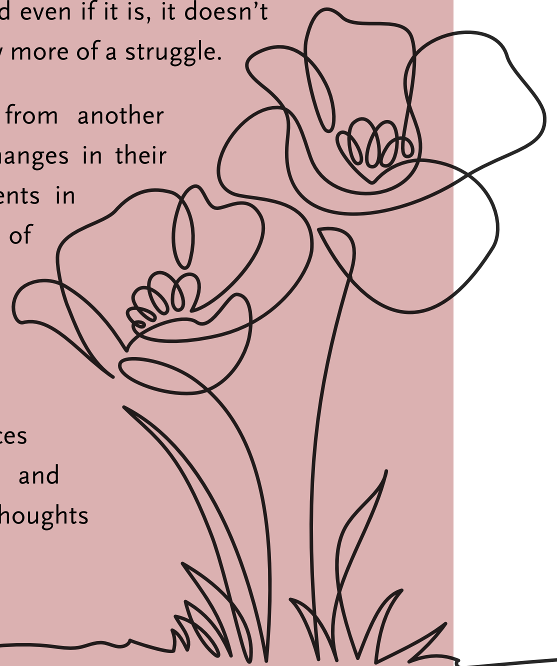
I like to compare it to walking through a meadow. Sometimes you're walking through the flowers, sometimes you're just walking through grass, and sometimes the grass gets really tall. Sometimes there's something under that grass and you step in it and get a bit stuck. Then you might get out of that muck and keep walking, but there's still something stuck to your foot. Then it dries and you wash it off and you keep going. You're constantly in that ebb and flow, up and down. It changes with every step, especially in the first year. It's very, very common for you to go through all those different phases many times.

LD: Many of our families have an additional diagnosis on top of Down syndrome. Often it's autism, but there are countless others. And that can be so hard to deal with. They tell us, "Okay, we just got our footing with Down syndrome, and now the rug has been pulled out from underneath us again." It's just layer on top of layer on top of layer, and they're like, "How do we get out of this hole?"

SF: And the people around them, friends and family, may not understand. In our society, we have this idea when it comes to loss or any other type of negative stimulus: suck it up. Get over it. As if anybody could.

I've heard well-meaning people tell parents, "Well, at least you know now, and you can do something about it." Well, that's not always the case. And even if it is, it doesn't change the fact that life is now more of a struggle.

LD: Let's talk about grief from another angle. Parents may notice changes in their relationships with other parents in their social circle. If friends of the family also have kids, and those children are developing more typically, this can be a painful reminder of the differences and can lead to isolation and withdrawal. What are your thoughts on this aspect of grief?



SF: That can be so hard. You may all have kids that are two, three, four, and you're all on the same page, more or less. Then as time rolls on, there begins to be a more noticeable difference, and it increases with every year. You may start to feel left behind, and you drift apart.

It was challenging for me personally, as I grew up with a twin brother who had special needs. At times I had to take him with me, be his caregiver and his sister, and still be my developmental age and engage in social relationships. I watched my parents trying to figure out how to do sports, how to manage family functions, and how to set both he and I up for success. It didn't leave a lot of time or energy for their own social life. It's a very challenging thing for any family to go through.

I think that's why it's so important to find your tribe. Find those people who will accept your family for who you are, and who want to be a support. In many cases, it's a small tribe, and it may not include the people you thought it would. That can really be difficult. But it's about quality over quantity.

LD: As adults, we often don't expect to have to change our social circle. We may think, "I have my friend group and I'm not planning on switching that." But then these changes happen and it's a whole other unexpected shift. And it's not just friends, either. Family dynamics change; family members may not understand what you're going through, or how to relate to your loved one with Down syndrome.

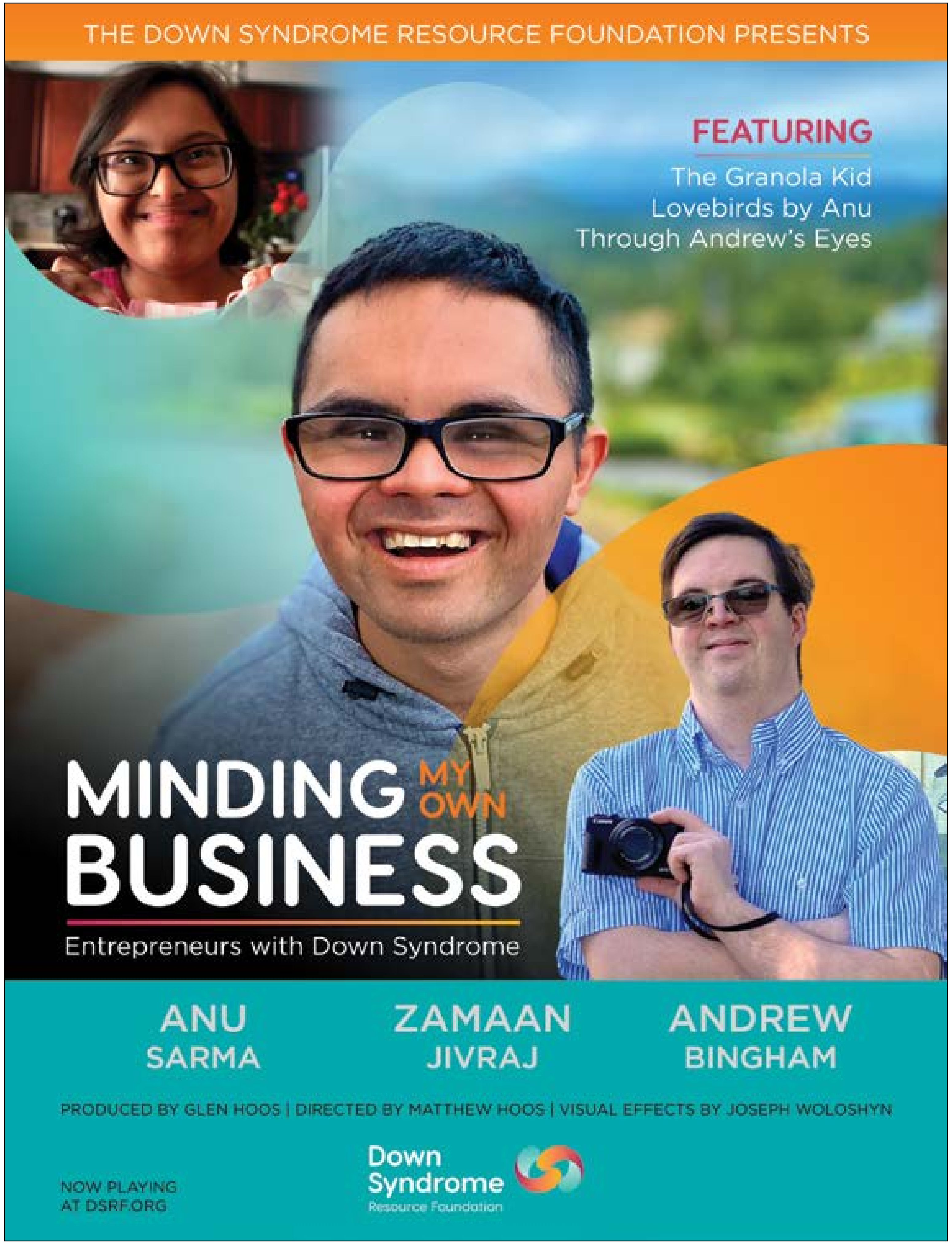
SF: Exactly. That's why those people who do understand are essential. They are a lifeboat.

LD: Let's close by talking about what to do when two people have different grieving styles: in this case, the two parents. We've talked with families who are heavily grieving, and one person really wants to share openly and widely with others and talk through all the details because that's how they process it, while the other person doesn't want to talk at all. That's not how they cope. It creates a point of contention between the two people who, ideally, should be on the same team and moving forward together.

SF: I think that that's probably one of the most difficult areas that I deal with when I'm working with families who are grieving as a family unit. I try to help them understand that everyone goes through their own process individually, and it's not wrong. It's okay for this person to want to talk openly and this person to want to be quiet.

It is so hard for people to understand others' grieving styles. When you are deep in grief, it feels like that's the whole world. You look outside and go, "Oh, the world is still moving around me. How is that possible? Don't they know what's happening in here?" Or you look at your partner and say, "How can you have moved on already?" You may even know that everyone does it differently, but saying it and feeling it are two different things.

Sadly, we have seen relationships between the parents not last because it becomes such a point of contention. We need to learn how to grieve in a way that gives space to ourselves and others. We have to accept it and say, "I'm going to give myself permission to grieve the way I need to grieve, and I'm going to give you permission to grieve how you need to grieve." There will be pain points, for sure, but if we can be honest with each other and keep this mindset, we can work through them together.

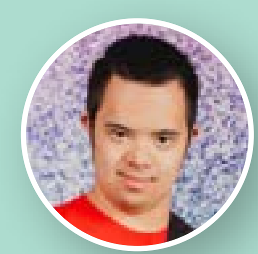


WE L♥VE OUR CAREGIVERS:

A SELF-ADVOCATE Q&A

Featuring...


Aaron
Burnaby, BC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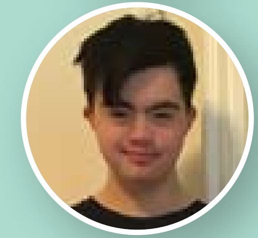
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Dave
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Monika
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WHO HELPS YOU WITH THE BIG AND LITTLE THINGS IN YOUR DAY?

Kelsey: My parents help me with my day. The best support and caregiving I get is from my family.

Monika: My family is very important to me. They help me when I need help with anything. My brother helps me with my computer, and my mom makes dinner and drives me to school and to swimming. My dad helps me walk our dog Scout. My dad has also helped me learn to ride a bike. I also love to bake with my aunt. My mom helps me with my bracelet company called "I AM BRAVE BEAUTIFUL," and with my modelling.

Aaron: My mom helps with my health, fun activities (like going to movies and restaurants), driving, and making me meals. My dad helps me with the heavy lifting stuff like workouts, playing NHL video games, and watching sports together. My sister looks after me when my parents go away.

Rae: My parents and my brothers.

Jason: My mom.

Jassi: My sisters, mom, and cousins. They help me all day.

Dave: Mom, dad, my sisters, and my cousins.

Darryl: I have my mom, dad, and my two brothers.

Zamaan: Mom, dad, and my brother Keyaan. My DSRF family helps me at school.

Harold: Dad and mom.

Anastasia: My mom and dad.

David: My mom.

Sid: Mom and dad.

WHAT DO YOU APPRECIATE THE MOST ABOUT THE PEOPLE WHO SUPPORT YOU?

Kelsey: I appreciate my family the most and my boyfriend Paul as well. My biggest joy is to be an Auntie for my nephew Bowen.

Monika: I appreciate everything about my family. We love playing games and going for long hikes with our dog. We go biking together as a family and in the winter we go skiing together. My family is fun and I love doing everything with them.

Aaron: I appreciate their attitude and they think I'm a great son and brother.

Rae: My family watches me perform on stage and they give me the best hugs.

Jason: She works hard and does meetings all day but still helps me.

Jassi: They take me to the beach, café, concerts, and fun things together. It's better with them.

Dave: I love going for walks together and staying healthy.

Darryl: Mom is helpful, dad is a good teacher.

Zamaan: They encourage me.

Harold: I feel supported and loved.

Anastasia: I feel happy and it makes me cry. I feel loved.

David: Mom is busy and works but looks after me. I feel happy.

Sid: My mom helps me and cooks food for me, and it makes me feel happy.

WHAT DO YOU DO TO HELP CAREGIVERS WITH THEIR DAY?

Kelsey: I help caregivers because I'm really nice to them and I give great advice.

Monika: I help out around the house. I make my bed in the morning and help with cleaning sometimes.

Aaron: I do chores like taking out the garbage and recycling, unloading the dishwasher, and babysitting my dog. On Thursdays I make my bachelor dinner for everybody.

Rae: I help my parents get groceries.

Jason: I mow the lawn and do my chores.

Jassi: I love them.

Dave: I clean.

Darryl: I help with the dishwasher at home, and I help fold the laundry.

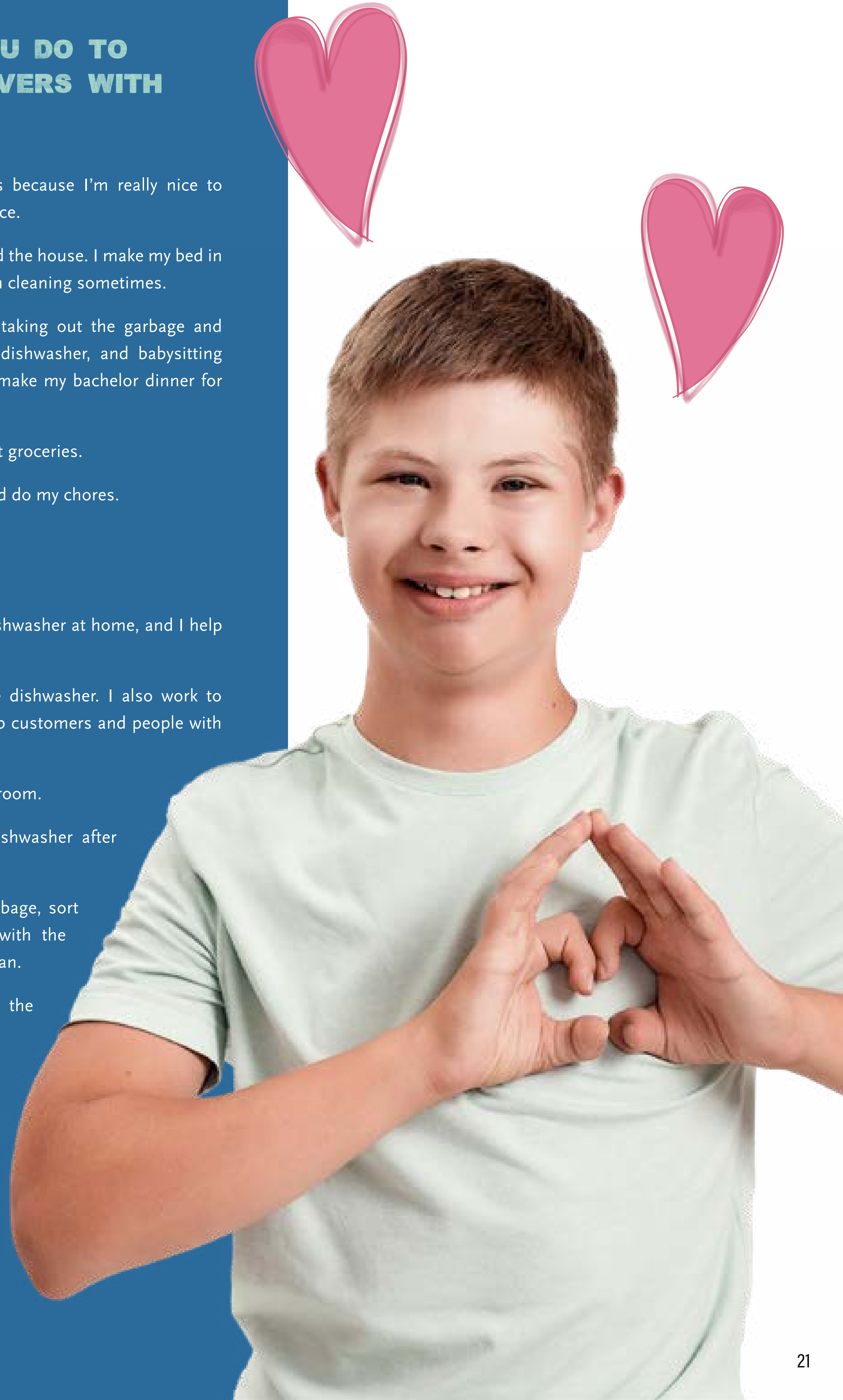
Zamaan: I help with the dishwasher. I also work to make my granola and help customers and people with Down syndrome.

Harold: I clean up in my room.

Anastasia: I load the dishwasher after every meal.

David: I take out the garbage, sort the recycling, and help with the compost bin to keep it clean.

Sid: I make tea and do the dishwasher.



Home for the Holidays

Taking the Stress Out of the Festive Season

An outdoor celebration in December during Covid - Yona and Danni in matching winter coats from mom!

Yona and Danni's Holiday Story

My older sister Danielle (or 'Danni' within our family) celebrates her birthday in December, as do I and our older brother. So December has always been a big and busy month for all of us. We celebrate birthdays starting with Danni's, and ending with mine. We also get together as a family to celebrate Hanukkah in December.

With COVID we had to switch from a bigger extended family celebration to smaller activities. A great thing about Hanukkah is that it lasts eight nights, so this means eight chances to light candles and sing together to celebrate the Festival of Lights. Instead of big presents, growing up we used to get smaller gifts each of those days. My sister Danni and I would often get different versions of the same gifts - matching clothes or toys. As grownups, we switched to focusing on little things for adults, and gifts or gift cards for the kids in the family – Danni has many nieces and nephews – but the candles, food, and singing all still happen for everyone.

When we lived together growing up, it was easy to celebrate Hanukah every night. My sister now lives in a supported apartment not far from my parents, my family, and my brother's family, but realistically, we don't see each other every night now. We have found that some smaller events work better than one big event with a lot of people. And we celebrate birthdays and Hanukah separately.

Danni is very excited about the holidays before they happen, so naturally she asks about them. She wants to know details like who is coming, who will take her, what is she going to wear, and who will help her get dressed up. These are important questions. I think we have had to remember that these questions signal that she is thinking about it and feeling anxious at the same time as being excited. And she may need to hear the answers more than once. And really, that is ok.

Things started to get a bit too stressful at one point for my sister - and maybe for all of us, when we combined birthdays and Hanukkah. Holidays change over time for most people, as does our capacity to cope with them. What we do during the holidays doesn't have to mirror exactly what we did last year, or what we did ten years ago. The important part is that we have fun and feel connected. Personally, the quiet candle lighting together with the prayers and the songs is one of my favourite things, and I think my sister feels the same way. If we don't get it quite right on one of the nights of Chanukah, we can always do it again the next day!

Laura and Kevin's Holiday Story

Our son Kevin is 29, and still a kid at heart when it comes to all holiday seasons, but especially Christmas.

We kick off a traditional Christmas in our household on December 1, with candy cane ice cream for breakfast that day. Kevin isn't much for sweets, but he loves to ring in that fun meal together. From there, the traditions continue throughout the month, with our eldest son's birthday on December 11. We cut down a live tree shortly after that date, followed by Kevin gathering all the ornament boxes and decorating the entire tree himself. He insists we all continue the LaChance Christmas tradition of no gifts under the tree until after bedtime on December 24. Edible chocolate ornaments are placed on the tree overnight, and stockings are filled with MORE traditions: toiletries, potato chips, some puzzle books, underwear, and small chocolate balls. Kevin doesn't eat the chocolate, but would be disappointed nonetheless if he didn't find them rolling around in the bottom of the stocking... have I mentioned he's very into traditions?

We find that piling on the magic during the season actually helps minimize any holiday stress. Large family dinners, Christmas baking, sleigh rides, decorating the house with lights, shopping, and wrapping gifts – we do it all, and it continues to bring a smile to his face and ours.

Now that our other three children are grown and don't live at home anymore, with two of them overseas, we can't always be together to celebrate. Sharing pictures and stories of Kevin during the holidays is something that, although virtual, still brings us closer. He loves to text and call his siblings, describing the festivities in great detail.

I hope Kevin never tires of these traditions. Seeing the sparkle in his eye and the spring in his step as he marches around in one of his many Christmas outfits gets us all in the spirit.

DSRF CORNER

DSRF Student Eric Bruneau Honoured with Klukas Achievement Award

Eric Bruneau has a collection of medals attesting to his accomplishments on the speedskating track. Now, the 32-year-old has a new treasure to add to his shelf: the 2022 George Klukas Achievement Award.

Eric, who grew up in Coquitlam with his parents and three sisters, has overcome many challenges in life. Born with Down syndrome, Eric endured three major surgeries before he was 15 months old, two of which were to correct a congenital heart defect. Over time, Eric also developed hearing loss, and began wearing hearing aids several years ago. But he has never let these obstacles hold him back.

Eric has had a lifelong love of sports. At the age of seven, he learned how to swim, skate, and ride a bike. That's also when he joined Special Olympics.

By the age of 12, Eric was competing in speedskating, with his dad as his coach. Through the years, Eric has earned several gold, silver, and bronze medals, having attended Special Olympics National Winter Games in Alberta, Newfoundland, and Thunder Bay.

Eric has also competed at the Special Olympics Summer Games in soccer and bowling. And if that's not enough sports, Eric also enjoys playing golf and baseball and is a rabid fan of his Vancouver Canucks.

As a young adult, Eric began attending educational programs at the Down Syndrome Resource Foundation, taking part in reading, math, cooking, yoga, and social groups. Through these programs Eric furthered his learning and developed his social skills.

Currently, Eric holds down three jobs. In addition to working at DSRF's front desk, Eric is also employed by Thrifty Foods and a local seniors' residence.

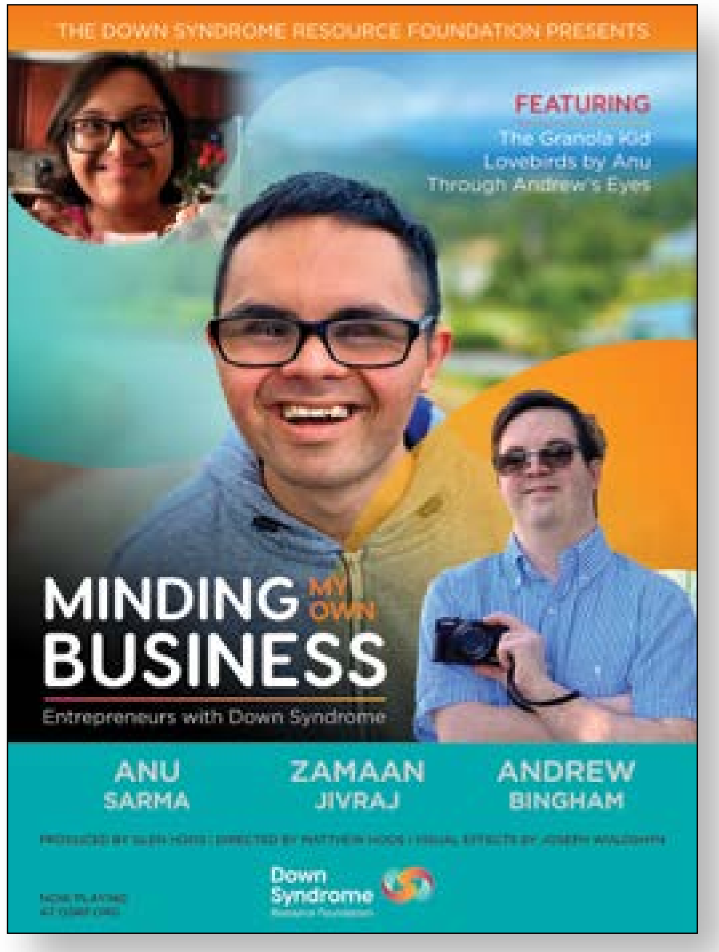
In his time at DSRF, we have been proud to watch his incredible growth as a person. Eric has become more flexible and willing to step in and help whenever needed. He takes unexpected change in stride and looks for every opportunity to lend a hand. He is a consistently positive presence around the building and has made many lifelong friendships.

Eric will tell you he has a good life. We can tell you that he has made our lives better. We are thrilled to congratulate Eric on winning the 2022 George Klukas Achievement Award.

Minding My Own Business: Short Film Debuts

In November, DSRF premiered the latest in our annual series of short documentary films.

Minding My Own Business: Entrepreneurs with Down Syndrome takes viewers inside three small businesses owned and operated by people with Down syndrome. We go behind the lens with photographic card maker Andrew Bingham (Through Andrew's Eyes), glam up with Anu Sarma (Lovebirds by Anu), and discover the recipe to Zamaan Jivraj's success (The Granola Kid).



Increasing numbers of people with Down syndrome are rolling up their sleeves and getting to work on their own businesses. Andrew, Anu, and Zamaan, along with those who support them in their endeavours, provide both inspiration and practical tips for getting a thriving company up and running.

Minding My Own Business is DSRF's follow-up to last year's short film *Feeling Down, Looking Up: Mental Health and Down Syndrome*, which has garnered over 60,000 views to date. DSRF also produced *Home Sweet Home: Independent Housing Models for People with Down Syndrome* in 2020.

Watch *Minding My Own Business* now at **DSRF.org/mindingmyownbusiness**.

Down Syndrome
Resource Foundation

FRIENDS OF DSRF

This fall, DSRF was thrilled to return to hosting our signature annual fundraising dinners in person. Up the Down Market returned to Vancouver in September, Calgary and Toronto in October, and Montreal in November. Collectively, over $500,000 was raised at these four events. Thank you very much to our generous sponsors, table purchasers, donors, and volunteers for making a lasting investment in students with Down syndrome. In particular, we would like to recognize major national sponsors the Air Canada Foundation, the Answer Company, Phillips, Hager and North, Mawer, Sun Life Global Investments/SLC Management, BMO Global Asset Management, CIBC Asset Management, Fiera Capital, Jarislowsky Fraser Global Investment Management, PIMCO, and Willis Towers Watson.

Thank you very much to long-time supporter the Lohn Foundation for granting $3,000 in support of educational programs for children and youth with Down syndrome.

We are grateful for the ongoing support of the John Hardie Mitchell Family Foundation, which has donated $3,000 towards programs and services for children and youth with Down syndrome.

The Stober Foundation has donated $1,000 to support the expansion of our programs and services for families in the Okanagan region. Thank you!

UPCOMING AT DSRF

Flourish for Life Campaign – *December 2022*

A Magical Morning – *December 15, 2022*

FIND US / TAG US

@DSRFCanada on all our platforms

DSRF.org

CDSS SPOTLIGHT

Your Generous Support Has Helped Us Change Lives

The CDSS Team was able to accomplish some ambitious goals in 2022 thanks to generous donations like the one we received from the Rexall Care Network.

Among our top projects this year was the research and redevelopment of 21 Welcomes, a critical resource that helps to educate and support new parents of children with Down syndrome across Canada. We were also able to launch a literacy program, new mental health resources for caregivers, our Love Means awareness initiative, and the world's first-ever Down syndrome employment network on LinkedIn - Inployable.

Without support from people like you and corporate community members like Rexall Care Network, we would not be able to accomplish these goals and provide support to the caregivers of our community.

Thank you for your unwavering generosity throughout the year. It means a lot to every Canadian you have helped. It means a lot to our Team at CDSS, too!

"Without initiatives like RCN, we would not be able to provide resources to caregivers in the Down syndrome community, who make sure that independence, wellbeing, and inclusion are achieved. RCN funds have helped us ensure that caregivers have access to reliable information and impactful programming supportive of their needs. This is vital because people with Down syndrome thrive with support from those around them."

- *Pamela Massaro, CDSS Senior Manager of Fund Development and Donor Engagement*

Since its inception, the Rexall Care Network has dedicated over 20 years and raised over 20 million dollars to support health and wellness initiatives. In 2019, they changed their mandate to focus specifically on providing support for caregivers, an often overlooked but invaluable pillar of our healthcare system. Since then, Rexall has raised over $1,400,000 in support of caregiver initiatives in local communities.

"Day in and day out, millions of Canadians provide unpaid care to a loved one. The Rexall Care Network brings greater focus, support, and resources to these important people, the caregivers. That's why we're proud to support CDSS, with its aim to provide information and connections to people with Down Syndrome, and those who care for them."

- Frank Monteleone, SVP & Chief People Officer at Rexall.

What can you do to help support caregivers in the CDSS community?

Making a personal gift or corporate donation, hosting a fundraiser, and spreading the word through social media are all excellent ways you can help to create awareness and support for our initiatives.

To learn more about the Rexall Care Network, visit **Rexall.ca/carenetwork.**

Introducing Inployable: The World's First Down Syndrome Employment Network on LinkedIn

In October 2022, we proudly launched Inployable, the new digital Down syndrome employment network.

The Inployable network was created to help overcome the difficulties jobseekers with Down syndrome face in the traditional recruitment process by providing a space where they can be visible and allow employers to connect with them directly.

> **Over 50% of Canadians with Down syndrome can't find a paying job.**

At Inployable.com, a person with Down syndrome can request the support of a LinkedIn Coach who will assist in building a LinkedIn profile and adding it to the Inployable network. An inployable profile is enhanced with features like displaying caregiver and supported employment agency contact information. Inployable profiles are also showcased to employers within the network who are looking for potential employees with similar skill sets.

With the largest labour shortage in North America happening right now, it is a better time than ever for Canadians with Down syndrome to be recognized as a reliable and skilled workforce.

Inployable brings digital visibility to jobseekers with Down syndrome who were previously considered less capable and less valuable to a workforce. Access to employer resources will also be available to support a shift in recruitment practice thinking.

Visit **inployable.com** today to join the network or learn how you can support Inployable by visiting our website at **CDSS.ca/Inployable**.

Your Impact in Action

Your generous support has allowed us to help the caregivers in our community in 2022 in many ways, such as:

- Providing new mental health and wellness resources for caregivers
- Investing in the redevelopment of resources for expecting parents
- Promoting self-care tips, information, and awareness through social media
- Initiating advocacy efforts around the Registered Disability Savings Plan
- Amplifying the voices and experiences of fathers & celebrating their contributions
- Creating a literacy program to support both caregivers & people with Down syndrome

Canadian Down Syndrome Society
Société canadienne de la trisomie 21

GIVE THE GIFT OF LIFE-CHANGING PROGRAMS

This holiday season, make a gift to CDSS in the name of your family member or friend and you'll be giving the gift of life-changing programs to Canadians with Down syndrome.

Our cozy CDSS Socks also make a great gift! Plus 100% of the proceeds from our partners at Friday Sock Co are invested back into our programs and resources. Visit **FridaySocks.com** to buy a pair!

JOIN THE CDSS COMMUNITY

Sign up to stay connected with new program announcements, important resources, and upcoming events.

CDSS.ca/SignUp

FOR ALL THAT YOU DO,

Thank you Caregivers

- FROM THE CDSS TEAM

FIND US / TAG US

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CDSS.ca

Donate now to help children with Down syndrome

Flourish for Life

Down Syndrome
Resource Foundation

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