



Dear New Parent,

On behalf of Down syndrome Outreach, congratulations on the birth of your baby! We understand the many feelings that new families have, and the questions and concerns that may arise as well. We are pleased to offer you this New Family Welcome Packet, which provides you with local resources and some information about newborns with Down syndrome.

Down syndrome Outreach (DsO, a program of The Arc of Whatcom County) exists for individuals with Down syndrome and their family members...from birth through life. The mission of DsO is to advocate for the rights, promote the potential and abilities, and create a supportive and inclusive community for people with Down syndrome, their families and individuals whose lives include a person with Down syndrome.

This packet is full of information, which can be overwhelming. As a community of families we are eager and ready to help provide support and networking, and to be a resource for you and your family when you are ready. With annual events, workshops, our lending library, family gatherings, and a New Family Reception, we focus on ways to celebrate and honor people in our lives who live with Down syndrome.

As one local mother says, it is important to remember, "They are a baby first - a new member of your family - diagnosis second." Enjoy the precious moments of a new life. Take time for yourself and your beautiful baby. The road ahead, as with every baby, is full of excitement, the unknown, and can be as bright and beautiful as we make it.

We hope to have the chance to meet you and your baby soon. Until then, we hope the resources in this folder are helpful. If you need anything at all, please don't hesitate to contact us.

Always Our Best,

Jessika Houston, DsO Coordinator & DsO Advisory Team

Down syndrome Outreach (DsO), The Arc of Whatcom County



**Members of the Down syndrome Outreach Advisory Team answer the question:  
If you could say anything to a new parent or family member, what would you say?**

Really, here's the thing: you never know who your child is going to be. We think we'll know. We make predictions; we tell stories about anticipated future, placing our child in our own narratives. When a child is born with Down syndrome, sometimes it can feel like the bottom has dropped out. But really, you get this gift - wrapped in complicated layers - of a clean slate. This child will be their own person in the world. They will amaze you and challenge you, and you will find SO many things to celebrate along the way.

*Gretchen, Mother*

Your baby has just been diagnosed or born with Down syndrome, but you have no idea the potential he or she has. Don't give up on the dreams you have for your child. She can be a cheerleader, homecoming queen, and prom queen. I know because my daughter has achieved all of these things. Dream Big!

*Heidi, Mother*

Be patient and know, "their pace, not mine". Love and nurture them, but trust that your child will learn the difference between right and wrong in time. Teach them and guide them the best you can, let your child know that he or she is loved, and let them be true to themselves ...Help them grow... don't limit his or her potential...unlock it.

*Laura, a woman with Down syndrome*

The road ahead, as with every baby, is full of excitement, the unknown, and can be as bright and beautiful as we make it. It requires patience, love, acceptance, giving and getting support. It will teach you more than you ever expected, and bring you more joy than ever thought possible. It will surprise you, and bring you to tears from laughter and tears from frustration. And you can't imagine a world without them. Just as with any child, or brother or sister. My brother is an actor, singer, and incredible dancer. He loves to discuss the weather and explore outside ...and he has an awesome 3 point shot! Always set the bar high - they can reach it!

*Jessika, Sibling*



- 1) Everyone has such different needs and ways to work through the early days of a diagnosis that is unexpected. What helped me tremendously in the early days of my son's life, and still does now, is having a peer group of parents who also have a child with Down syndrome. The opportunity to share medical information, therapy tips, resources, and advice is very helpful but, more importantly, at least in my eyes, is the emotional support and understanding that you gain from other parents who truly "get it".
- 2) I try not to feel bad or guilty about advocating for my son. No one else knows him the way I do and, probably, no one else will speak up if I don't.
- 3) I always speak at meetings and appointments (school, medical, or otherwise) about how amazing my son is and how capable he is. I think it's important to frame him as positively as possible. That is how I want others to view him and for him to see himself that way as well.

*Barbara, Mother*

Dear family who just welcomed a brand new little baby....a child who happens to have Down syndrome. Be humble in your thoughts and lovingly welcomed in joining us all on a journey you never knew existed. You have suddenly taken the left turn in at the fork in the road you surely didn't anticipate but it will be full of so much love and just as much excitement. Patience, just be prepared to have patience...never in your life will you as a parent need to practice so much patience, and I'm not talking about the kind you have while waiting in the world's longest line at the grocery store. This is a different kind of patience: one that pierces right into your heart and reminds you to sit back and slow down and appreciate every little thing for being just so. Be strong, because your baby needs you so much. You will, as any parent to a brand new little baby, be overwhelmed, but add on all the things you suddenly think your baby won't do like other babies.....and all the things you wonder if they will do as a child and as an adult, but that's where the patience is going to help you. Your child, your brand new precious little baby, CAN and WILL do anything you have the patience to support him or her in. This Down syndrome journey is just a new path; embrace it and enjoy every single second.

*Krissy, Mother*