

Pregnancy and Autism: A Guide for Autistic People Before They Give Birth

Authors:

Maxine Share, Autistic Self-Advocate, former Autism Consultant, Mother of four, including an Autistic son and Grandmother of 11 beautiful grandchildren, including four who are Autistic.
Dr. Fakhri Shafai, Chief Science Officer of AIDE Canada

Background about this toolkit:

This toolkit was requested in a focus group AIDE Canada conducted with Autistic people. They asked for a resource that would go beyond the typical “what to expect” during pregnancy and instead would provide guidance on the unique experiences an Autistic person may have while pregnant. We are also using identity-first language to refer to Autistic people as previous studies have shown that this is the preference amongst adults on the autism spectrum. We are choosing not to limit the language in this toolkit to “women” or “mothers” to be inclusive of pregnant people of all gender identities.

Contents:

1. Introduction
2. What does the latest research say about Autistic people and pregnancy?
3. How could being pregnant impact my sensory processing differences?
4. How can I feel more connected to what is happening inside my body?
5. How can I support my physical and mental health during my pregnancy?
6. How can I find support if I have a miscarriage?
7. How do I best bring up my concerns and communicate with medical professionals during my pregnancy?
8. How do I best reach out for support during my pregnancy?
9. Planning for the birth
10. The Birth
11. Postpartum at home
12. Conclusion
13. Additional Resources
14. Suggested Reading
15. References

1. Introduction:

Jane is a 30-year-old Autistic woman who has just discovered she is pregnant one year after she and her partner first started trying to have a baby. She took the pregnancy test in a bathroom

stall at work, and is now experiencing a flood of emotions, including shock, anxiety, and joy. After so many months of disappointing negative pregnancy tests, she can't quite process the good news that she is, in fact, pregnant and growing a human life inside of her. There are so many decisions to make, such as how to share the news with her partner (should she phone him at work or wait to tell him at home?). She suddenly feels immobilized with anxiety about what lies ahead. Her cheeks feel hot. Much of her anxiety is from not knowing what comes next. Will she be a good mother? Will her baby be healthy? Will she lose the baby? Will she get a quick referral to an obstetrician? Should she choose a midwife instead? What should she do while she waits for an appointment? She has to know! Her mind and heart are racing as she takes several deep breaths, exhaling slowly to try and calm her body down.

Pregnancy can be both an exciting and scary time for all new parents. Many are worried about making sure their baby is healthy, if they are doing the right things to prepare for the baby, and if they are really ready to bring a new life into the world. For new parents who are also Autistic, there can be additional concerns about how pregnancy will impact their sensory processing differences and anxiety, if medical professionals will be supportive in the way they need, and if they will be able to maintain their physical and mental health throughout the pregnancy.

This toolkit will discuss:

- latest research about the experiences an Autistic person may have while pregnant
- sensory processing differences and how they may impact you during pregnancy
- tools for increasing awareness of what is happening inside your body during your pregnancy
- tips for supporting your physical and mental health during pregnancy
- guidance for how to find support after pregnancy loss
- strategies for discussing concerns and advocating for yourself with medical professionals
- how to reach out for support if needed
- creating a birthing plan
- what you may experience while giving birth
- postpartum at home
- additional resources and suggested reading

2. What does the latest research say about Autistic people and pregnancy?

Unfortunately, the topic of pregnancy in Autistic people has only recently been explored by researchers. This may be in part due to the history of gender bias in autism research focusing on males, so other gender identities have often been excluded from studies. In recent years, some studies have looked at pregnancy outcomes for Autistic people, and a few studies have explored the personal experiences of Autistic people during pregnancy. While normally AIDE Canada would describe the trends in the research, there are so few studies to consult that we instead have given a brief summary of each recent study available and discuss their findings.

Pregnancy outcomes and health concerns:

A 2015 study explored data from births in Massachusetts between 1998 – 2009 of people with intellectual and/or developmental disabilities (IDD) and found that people with IDD were less likely to receive prenatal care in the first trimester, more likely to have preterm delivery, and more likely to have babies with low birth weight¹.

A 2018 study looked at medical birth records in Sweden from 2006 – 2014 and found that parents diagnosed with autism were at increased risk of preterm delivery, increased likelihood of cesarian delivery, and increased risk of preeclampsia (high blood pressure and/or damage to internal organs)².

Pregnancy experiences:

A 2017 case study out of Australia interviewed an Autistic person who had given birth and asked about their experiences. Challenges in communicating with medical professionals and accessing services, stress due to sensory processing differences (including differences in perceiving pain), and feelings of being judged by others were all identified as sources of difficulty for the Autistic parent³.

A 2021 systemic review (meaning a planned way to compare multiple studies about a topic) found thirteen studies that either discussed pregnancy experiences and outcomes or parenthood among Autistic adults. The review found that Autistic adults found it difficult to communicate with health care providers throughout pregnancy and birth. Autistic adults were also more likely to experience depression during and after pregnancy. The study ends with some recommendations for how to better support Autistic adults through pregnancy, which will be discussed further in later sections of this toolkit⁴.

A 2022 systemic review looked at over 2600 studies and identified only six that discussed the sensory experiences of Autistic people during pregnancy. Sensory challenges were identified as a key issue pregnant parents faced, as well as communication issues with healthcare providers and a lack of information and supports throughout pregnancy and after giving birth⁵.

A 2022 study compared the online survey responses of 417 autistic and 524 non-autistic parents about their pregnancy experiences. Autistic people reported that they experienced more sensory and physical symptoms during pregnancy, as well as higher rates of prenatal depression and anxiety. Additionally, autistic parents reported lower satisfaction with prenatal healthcare and relationships with healthcare professionals⁶.

Putting the research together:

The lack of studies in this area makes it hard to draw firm conclusions about health outcomes in pregnancy. The communication and sensory challenges described by Autistic people in some of the above studies are likely due to healthcare settings not meeting the needs of Autistic

patients, but further research is needed to identify which aspect(s) of the healthcare experience are leading to these difficulties. It is unclear whether the higher frequency of preterm births, low birth weights, or preeclampsia are related to difficulties accessing or communicating with medical professionals. It is also unclear whether some of the medications that many Autistic people are on for things like epilepsy, anxiety, and depression play a role in the higher rates of preterm births. Future studies should include more Autistic adults with lived experience of pregnancy. There should also be more in-depth statistical analyses of the role that systemic factors and inaccessible healthcare settings may have on pregnancy outcomes for Autistic people.

3. How could being pregnant impact my sensory processing differences?

*Jane is excited to become a mother but has had a lot of unpleasant sensory experiences related to her pregnancy. People are always touching her, rubbing her belly as though it was something separate from her. She finds it very intrusive and aggressive, but cannot find the words to tell people not to do it. She has had to change her diet to do the very best job she can of growing a baby, and she finds the textures of some of the foods intolerable. The doctor told her to eat food rich in calcium. She is lactose intolerant, so milk, yogurt and cheese are out of the question. She can not tolerate the smell of eggs, so they are not an option. Broccoli has become a staple in her diet. The doctor put her on additional calcium in the form of a supplement. She **was unable to swallow the large pills**, and she took those, along with the prenatal vitamins, to a **compounding pharmacist who made them into smaller pills** that she could more easily swallow. During her first trimester, she often felt nauseous, and this caused her great anxiety, as she has a fear of vomit. It was the worst part of her pregnancy experience. Jane still can't stop thinking about her first visit to the obstetrician. She had to wear a stiff, itchy hospital gown while she had both an internal (pelvic) exam and a breast exam. She could barely tolerate someone touching her. The doctor did not explain why she was doing these exams. Jane also found the light the doctor used during the exam to be very bright. She closed her eyes throughout the process, but still left with a headache. Jane couldn't wait to get dressed back into her comfortable pregnancy leggings and oversized cotton t-shirt. At the end of each appointment, she had to have a blood draw. She didn't feel any pain from the needle, but the tight band the blood tech tied around her arm to make the blood draw easier made her stomach turn. She dreaded it every time. She also didn't look forward to the time in the waiting room prior to her appointment. The seats were so close together, and everyone was so chatty. Having people in her personal space bubble caused her lots of anxiety. The only good part of her doctor visits was when the doctor announced that baby was doing well. She loved hearing her baby girl's heartbeat.*

As a pregnant woman, she found her sensory sensitivities were heightened. She could not tolerate uncomfortable clothing and could only wear Crocs or runners on her feet. She couldn't drive past a fried chicken restaurant because the smell made her nauseous throughout her pregnancy. While she always found loud noises unpleasant, this escalated during pregnancy. She could no longer tolerate the hum of conversation in restaurants, or her co-workers exchanging small talk with each other as she tried to work. As her tummy grew, she found it

increasing challenging to understand the space she occupied, and would often bump into people on the bus or in line-ups at the grocery store. She was drained by the time she got home from work each day, and she found herself withdrawing from both touch and conversation from her partner. She experienced social and sensory hangover almost every night. This was a result of the constant overwhelm experienced by her heightened experience of the sensory world, and the rising social demands to participate in small talk about the pregnancy from coworkers and strangers alike. Her understanding partner would make dinner and bring it to her, and not demand that she socialize. The calm and quiet atmosphere at home allowed her to recharge for the next day.

Sensory processing differences have been described in autism for many years, but it is only since 2013 that they were considered part of the core criteria for diagnosing autism⁷. This means that few studies have looked at pregnancy and sensory experiences at all, with the 2022 study described above being the first to summarize what we know on the topic.

We do know that general sensory processing differences in autism often start in childhood and continue into adulthood⁸. Autistic people also tend to have sensory processing differences in more than just one sensory system⁹, for example a person may experience sensory overload from too many simultaneous noises (auditory system) and bright lights (visual system). A person can also be underwhelmed by sensory information, which may impact their ability to perceive things like whether a surface is hot or cold (tactile system) or internal body signals like knowing when they need to use the washroom (interoceptive system). For more information on how the different sensory systems can be impacted in autism, please see [AIDE Canada's "Sensory Processing Differences in Autism Toolkit"](#).

Another aspect of sensory processing differences in autism is that a person's sensitivity to different sensory systems can fluctuate throughout day to day and even hour to hour. For instance, a person's ability to recognize pain may be very sensitive in the morning, but they may not recognize that they have been injured later that day. These challenges in recognizing what is happening in their body may make it difficult to feel connected to what is happening throughout the pregnancy. It may also make it challenging to know if something has changed and they need medical attention.

In the general population, pregnancy can change how people experience sensory information, with one of the more common issues being certain smells making pregnant people feel nauseous. It is unknown if those sensory system changes are the same or more extreme for Autistic people who are pregnant compared to the general population.

If you are pregnant and want to know how your sensory systems may be changing throughout your pregnancy, we suggest keeping track of your sensory experiences throughout the day and paying attention to any trends that you notice. In the link below, you will find a table that describes each sensory system, examples of how you can know if that sensory system is overwhelmed or underwhelmed, and a place to take notes about what you noticed about that sensory system before, during, and after the sensory experience. Keeping track of the time you

noticed it impacting you can be helpful too. For instance, you may notice that you dislike the smell of cooked eggs in the morning it makes you feel nauseous--but smelling them later in the day does not bother you.

There may be positive sensory experiences during pregnancy that you would like to track. For instance, you may find that you are better able to enjoy the scent of things you like, like flowers or cut grass. Some people enjoy the feeling of their baby kicking. You may have always enjoyed a good foot rub, but now you are craving them every day, along with a deep tissue lower back rub. Keeping track of the positive or negative sensory experiences can be helpful in identifying patterns and finding ways to support your needs.

[Hyperlink: Sensory chart](#)

4. How can I feel more connected to what is happening inside my body?

Generally, Jane is unaware when she needs a drink, and almost never feels thirsty. She would often go a whole day without anything except a single cup of coffee to drink. Jane found it challenging to drink the eight to 12 glasses of water she was asked to consume, but she did it by creating a schedule and using a timer to remind her to drink. She was determined to have a healthy pregnancy. Although she struggled with an eating disorder (she was once hospitalized with anorexia nervosa), Jane was determined to eat exactly as the OB instructed. She was vigilant about keeping to the calorie count—which included an extra 300 calories for the baby—even though she rarely felt hungry, especially during the workday.

Prior to becoming pregnant, Jane would hold her urine in favour of work or any other task she had to do. She rarely felt an urgent need to use the restroom. Since her middle trimester, she began to experience that more urgent need to void. She was so surprised by the experience that she didn't always move as fast as she needed and had a couple of accidents by not making it to the washroom on time. Jane had terrible abdominal pain in her middle trimester as well. She made a trip to the emergency ward where doctors determined she was chronically constipated. They were surprised that Jane had been able to tolerate the amount of stool that had built up.

Interoception is what allows us to know the internal state of our body, like whether we are hungry, thirsty, or need to use the washroom. It is also the system that we use to know when we have internal pain, like stomach cramps, or if our internal state has changed, like if you are feeling hot or your heart is beating fast. Studies have shown that Autistic people can have challenges in processing signals from their interoceptive system, which may impact other co-occurring conditions like anxiety disorders¹⁰⁻¹¹.

As you may imagine, being pregnant means that internal body changes are happening as your pregnancy continues. The uterus will grow throughout the pregnancy, which will put pressure on your bladder, move internal organs, and cause the bones and ligaments in your hips to stretch and separate as you get closer to the due date. For people who have challenges with

perceiving information from their interoceptive system, they may not recognize when they need to use the washroom more frequently due to pressure on their bladder. Or they may not recognize that they are having contractions until they have been in labour for some time.

The interoceptive sensory system has not received much attention in studies until recently, but a group of researchers and Autistic self-advocates out of South Australia have developed the 'Ready to Learn Interoception Kit' to help improve your awareness of and connection to your interoceptive system. These exercises were originally developed as part of a region-wide curriculum in primary schools. Students who were taught the exercises and techniques were able to recognize when they were becoming overwhelmed or anxious and learned how they could calm themselves down before they resorted to coping behaviours, resulting in an over 80% decrease of students being sent home for behavior that was perceived as negative by others in school¹².

While the 'Ready to Learn Interoception' curriculum kit was designed for use in the classroom, the exercises it contains can be used by anyone hoping to develop their interoceptive skills. Additional activities have also been developed by these researchers. AIDE Canada worked with leading Australian researcher and Autistic self-advocate Dr. Wenn Lawson to turn these materials into an online interoceptive skills training course called 'Understanding What is Happening Inside Your Body'. Please see the 'Additional Resources' section below to access these and other tools.

5. How can I support my physical and mental health during my pregnancy?

Jane was mostly happy during her pregnancy. She always wanted to be a mother and couldn't wait to meet her daughter. However, Jane worried a lot during her pregnancy and her anxiety often descended in the evenings when looping, catastrophic thoughts about her pregnancy would overwhelm her. She was terrified about the delivery, and the fear would wash over her at night when everything was quiet. She worried most that something would interfere with her experiencing the ideal birth she had planned. Her birth plan included having only her and her partner present, an unmedicated birth, and no episiotomy. The thought of having someone cut into and then stitching up the skin between her vagina and anus was frightening to her. She was also terrified at the idea of having an epidural—a needle inserted into her spine to block her labour pain. She attended birthing classes with her partner so she could be as prepared as possible for the labour and birth experience. Random strangers, friends, and co-workers felt the need to share their pregnancy and birth stories, and some of them scared the heck out of her. She practiced her breathing exercises every day without fail, and she began doing Mindfulness exercises, too. The whole purpose was to allow her to cope with any pain she might have so she could avoid an epidural. She would try to block out all thoughts of a C-section, a pre-term birth out, or sick baby, but they'd creep in and cause her great anxiety. She was prone to thinking of worst-case scenarios. During the quiet of night, she could feel the pounding of her heart and its

quickened beat whenever her mind wondered to those dark places. She could hear her breathing, and the sound of it increased her anxiety. As she grew in size, her breathing became more shallow and louder. She found it hard to tell if she was anxious or just feeling the experience of lungs getting pushed out of the way by a growing fetus. She found her reading and her constant research surrounding pregnancy and childbirth gave her a sense of control over this uncertain time in her life. Her birth plan anchored her. She would read it over and over to reassure her that everything was fine.

*Jane found progressive muscle relaxation exercises very helpful as she tried to calm her body down. She did not tell her doctor, husband or **doula** about her fears or her intense anxiety. She felt certain the doctor would want to give her medications, and there was no way she would take any. It wasn't good for the baby. Jane had her first-ever panic attack one evening when her husband was sleeping. She briefly wondered if the pressure on her chest meant she was having a heart attack, but because she read so voraciously about anxiety, she recognized her symptoms, which also included sweating, chills, weakness, and tingly hands as physical symptoms of a panic attack. She used self-talk to remind herself that the feelings would pass, and got out of bed to splash her face with cold water in the bathroom. She did not tell her doctor about this either. She didn't want to be flagged as an 'unstable mother'.*

*Besides panic attacks, Jane was healthy throughout her pregnancy, with a couple of minor exceptions. She got a very sore throat with a cold and refused to go to the doctor or even take a Tylenol. She didn't want meds anywhere near her growing baby. Another time, she had pain in her **sacroiliac** joint during last trimester, and it made it difficult to walk for a few weeks. That felt serious enough for her to go to the doctor, who suggested she go to a physiotherapist, who then advised her to walk less, rest more, change positions frequently (from standing to sitting), and to sleep with a pillow between her thighs. It helped a great deal.*

Jane credited her overall good health during pregnancy to her steadfast adherence to food and exercise guidelines. She ate more calories than was usual for her, something that was very difficult for given a history of anorexia. She ate even when she was not hungry and even if it made her anxious because she knew it was good for the baby. The monthly, bi-weekly then weekly weigh-ins were difficult, too, because of her history of an eating disorder. She was very pleased with herself when the doctor praised her rate of weight gain.

In addition to eating exactly the number of calories suggested, she refused to eat at restaurants (you never know what they put in their seasonings), or any processed foods. This included drinks, (she gave up her morning coffee and occasional soda; she never consumed alcohol, so this wasn't an issue), any canned foods (so much sodium and so many chemicals!), anything with trans fats, any kind of tuna (mercury—she was extra cautious). She started eating her beef well done, which was different from her preferred medium-well), no processed meats of any kind, and she washed her produce thoroughly before eating it. This included packaged pre-washed salad. Though the diet restrictions were tricky, she felt the sacrifice was worth benefits of a healthy baby and healthy pregnancy. As for exercise, Jane made sure she got in the minimum of 150 minutes of physical activity per week. This was easy to include as she switched

from driving to work to walking the 20 minutes each way in good weather. If bad weather got in the way, she was able to use her treadmill at home to get the exercise in for the day.

** A **doula** is a trained professional who provides information, emotional and physical support to a woman and her partner during her pregnancy, birth, and in the postpartum weeks.*

*** The **sacroiliac joint** links the lower spine and pelvis.*

Physical health during pregnancy:

There are many guidelines for how to stay physically healthy and what to do to promote your baby's health as they develop. Many of the guidelines are the same as what is recommended when you are not pregnant – like eating healthy, drinking lots of water, and getting regular exercise.

Some of the guidelines, however, are confusing and may be different depending on who you talk to. For instance, guidelines in some countries say that a pregnant person should never drink anything with caffeine, while in other places pregnant people are told that they can drink up to two cups of caffeine per day. In some places you may be told that you cannot have any processed meats or sushi, while others will say they are fine in moderation. Similarly, guidelines that were common for previous generations may no longer be supported by scientific evidence.

At AIDE Canada, we cannot make specific recommendations for what you can or cannot do or eat while pregnant. Instead, we recommend you look at the Public Health Agency of Canada's guide for having a healthy pregnancy and speak with your doctor for recommendations specific to you and your personal health concerns. This up-to-date guide is intended to answer any questions you have and provide resources for having a healthy pregnancy based on the current scientific evidence. You can access the guide by clicking on this link [here](https://www.canada.ca/en/public-health/services/health-promotion/healthy-pregnancy/healthy-pregnancy-guide.html):
(<https://www.canada.ca/en/public-health/services/health-promotion/healthy-pregnancy/healthy-pregnancy-guide.html>).

Mental health during pregnancy:

One of the biggest mental health concerns for pregnant people and new parents is depression. Hormone changes throughout pregnancy can cause mood swings, but those with a history of depression, difficult life experiences, and lack of social support are more prone to depression both during and after pregnancy¹⁴. Additionally, you may have had to adjust your prescription medications or even stop using them entirely while pregnant, which can also lead to mental health challenges as your pregnancy continues. Your doctor should be guiding any medication changes and checking in with you at each visit to make sure your mental health needs are being met.

It is important to share your thoughts and feelings with others so you can feel supported, which can be a challenge for some Autistic people. Think about a person in your personal life who you feel comfortable sharing your feelings with. It could be a partner, friend, or family member. If you can't think of anyone, is there a professional (therapist, social worker, etc.) you know that you can talk to? If talking to someone is difficult, is it better for you to write it out as a letter or email? Feeling supported is important for us all, but especially during and after pregnancy.

If you find yourself thinking that life is not worth living, please reach out to your doctor immediately or go to the nearest emergency room. **You can also call the suicide/crisis lifeline at 1-833-456-4566 or dial 988.** If you prefer not to phone, there is [an online chat option \(https://988lifeline.org/chat/\)](https://988lifeline.org/chat/) or you can **text 988 to speak to someone over text.**

6. How can I find support if I have a miscarriage?

One of the most heartbreaking experiences for expecting parents is if they have an unexpected pregnancy loss/miscarriage. According on one recent series of studies, the risk of miscarriage can be impacted by multiple things – including age of the pregnant person (under 20 or 35+), age of the person providing sperm (age 40+), BMI of the pregnant person (either very high or low), and those of black ethnicity¹³. Lifestyle factors like smoking, alcohol, stress, working night shifts, air pollution, and exposure to pesticides have all been associated with higher likelihood of miscarriage¹³. People who have no history of miscarriage are at lower risk (11%) of having a miscarriage compared to those who have had one or more miscarriages (up to 42% for people who have had 3+ miscarriages)¹³. Most miscarriages happen in the first trimester, which is part of the reason that some people recommend waiting until the 12th week of pregnancy before sharing the news.

One of the most common questions parents have following a miscarriage is what caused it. Chromosomal abnormalities (e.g., the fetus having too many or too few chromosomes) are found in 60% of miscarriages¹³. While some abnormal chromosome numbers can still result in a full-term pregnancy and a person with average lifespan (e.g., a person with Down Syndrome), most chromosomal abnormalities will lead to miscarriage or stillbirth¹³. Chromosomal abnormalities are more common in parents of advanced reproductive age, which helps to explain the increased risk of miscarriage with parental age. Other possible reasons for miscarriages include the embryo having difficulty implanting in the uterus or the immune system of the pregnant person mistaking the embryo for foreign cells and mounting an immune response¹³.

Unfortunately, in some communities there is still stigma associated with discussing miscarriages or stillbirths. This can lead many people to feel isolated or alone. Some people choose not to share the news as they may be faced with people asking them what they did to 'cause' the miscarriage or subscribing to old wives' tales about why it might have happened (e.g., "were

you lifting something heavy?”). People may say inappropriate things such as, ‘It’s all for the best. It’s nature’s way of getting rid of defective babies,’ or ‘Don’t worry. You can always try again.’ These kinds of comments can be devastating when you are grieving the loss of pregnancy, of these dreams. This lack of compassionate support can lead some to grieve alone. They don’t want to share the experience for fear of painful responses.

Sudden miscarriage is also an unexpected event, and Autistic people often do not do well with uncertainty, or changes to plans that were unexpected. It is important for pregnant Autistic people to be made aware of the possibility that miscarriages can and do happen, and to understand where and how to reach out for help if this is their experience. They should also be made aware that miscarriages can occur in up to 30% of pregnancies, and that healthy Autistic women can and do carry pregnancies to term and have healthy children.

If you experience a miscarriage or stillbirth, there are some resources that can help you process this loss. Many hospitals or reproductive centres offer grief support groups where other people who have experienced the loss of a pregnancy can discuss their feelings in a supportive atmosphere. Individual or couple’s counseling may be helpful for parents who need to process their loss outside of a group setting. There are also online support communities for those who prefer to process their grief more anonymously.

Whichever route of support you choose, please remember that the miscarriage is not your fault, miscarriages are extremely common, and that even with multiple miscarriages it can still be possible to carry a future pregnancy full term.

7. How do I best bring up my concerns and communicate with medical professionals during my pregnancy?

Jane was very nervous about her first obstetrical appointment. She had so many questions, but was often unable to speak in high anxiety situations. Knowing this could be a problem, she wrote out her list of questions in advance, and asked her partner to come with her to ask the questions and take notes. (While she could take notes, if she did so, she would not be able to pay attention to the doctor’s answers or ask good follow up questions.) She was always apprehensive meeting new people, and she hoped she would feel comfortable with this doctor. She learned that the first appointment would take about thirty minutes and would include sharing her medical history and letting the doctor know how she was feeling. Weight and blood pressure would be taken, and she could expect a pelvic examination as well. She wondered where time for questions would fit into this tight timeline.

The doctor she was seeing was highly recommended. Jane found her to be very friendly, but Jane felt very rushed. The doctor seemed to have a plan for every minute of the first appointment, and though she continually asked Jane, “Do you have any questions,” Jane was unable to respond. Jane’s partner asked the doctor if it would be okay to read a list of questions at the end of the appointment. The doctor agreed, but said time would be limited.

Jane was only able to have four of her two dozen questions answered at the first appointment. On her way out of the appointment, she asked the receptionist if she could email the doctor questions in advance of the next appointment or have extra time for her appointment to have questions answered, disclosing only that she has situational mutism. She was unsure if she wanted to disclose her autism diagnosis. She did not want to be disrespected or patronized, nor did she want extra attention focused on her in terms of her competency as a mother. She'd wait for a few more appointments to see if she trusted the doctor. Even if granted extra time, she would have her partner ask the questions if required to ask them at the next appointment rather than through email.

The receptionist got back to her and said she could provide the doctor with questions at the beginning of appointments, and she would try her best to get through them. While Jane thought this was a positive response, she began to see why some people choose a midwife rather than an OB for their pregnancy specialist. A first appointment with a midwife is generally an hour, giving lots of time for questions. Appointments feel less rushed and more focused on how the mother is doing. Still, Jane felt secure with all of the medical supports that the OB was able to provide, and she was content for now with her choice to opt for a doctor for this birth.

Some people, like Jane, have many concerns and questions they want to ask. Others are so overwhelmed that they don't even know where to start or what to ask. Your doctor will likely have some questions for you during the first appointment about your personal and family medical history, menstrual cycle, and prescription medications. They will also likely ask about your alcohol or drug use, caffeine intake, and areas you have traveled. They will do a physical exam and send you to a lab for blood work.

Questions you may want to ask your doctor may include how much weight you should gain at each stage of pregnancy, whether you will need to change your current prescription medications, what over-the-counter medications you are able to take, and whether you should be taking prenatal vitamins. You may also want to ask about optimal exercises, sex, food and drinks that are allowed, and what sort of activities you should avoid. It is good to ask about what pregnancy symptoms are to be expected and which symptoms are a cause for concern. You may also want to find out how they would like you to handle any future questions you have (e.g., send them via email before an appointment).

If you are considering working with a midwife, it is important to contact a midwifery practice and ask what their procedure is for taking on new clients. You may want to ask about their general approach to supporting birth givers and their families, how they work with medical professionals, and in which cases would they transfer care to medical professionals during labour.

If you are looking for support from a doula who can help support your emotional well-being and comfort during delivery, you may want to reach out to other people who have given birth in your area for recommendations. Consider meeting with potential doulas to explore how they

would support you, how they interact with doctors and/or midwives, and what sort of experience they have supporting neurodivergent parents.

Jane's second appointment was not much better in terms of time for questions. Although the doctor had the questions at the beginning of the session, she was only able to answer a few of Jane's questions. Jane began to wonder if disclosing her Autistic identity might encourage the doctor to answer her questions. She dearly wanted the additional support she might get (questions answered, dimmed lighting in the consultation room, step-by-step information whenever a test or procedure was necessary, for example), but was fearful of potential drawbacks of disclosing. If medical staff saw her crying, would they report her for being overwhelmed? After the birth, if she couldn't tolerate a nursing infant on her breast, would she be considered unfit? There were so many uncertainties, and these weighed on Jane.

Jane decided she needed certain supports in order for this pregnancy to be a comfortable and positive experience. She chose to disclose symptoms rather than the over-arching diagnosis of autism. She told the doctor at her third meeting that she has sensory processing disorder, anxiety in medical settings, and situational mutism in high anxiety settings.

The choice to share this information was very helpful. The doctor encouraged her to list her sensory sensitivities, and even suggested some situations that might be challenging, such as multiple people in the birthing room, bright lights on at the time of birth, noise from other mothers in labour and the clanging sound of medical instruments). She asked Jane why she has anxiety in medical settings, and Jane shared an unpleasant experience from her childhood. The doctor was very understanding and supportive, and said she'd like to help change her opinion of doctors by making this as positive an experience as possible. From her third appointment on, Jane felt much more at ease with the doctor, who always asked for her list of questions. The doctor was careful to explain reasons for every instruction she gave to Jane, and what she could expect at each ultrasound or lab test.

Jane feared that disclosing her autism diagnosis may lead to her medical team deciding she was an unfit mother. Unfortunately, this is a fear shared by many other new parents with any diagnosis, not just autism. The stigma that is attached to autism (or other diagnoses) has led some to distrust medical professionals. This fear unfortunately may mean that a person may not get access to all the supports that are available to help new parents.

Some hospitals have a reproductive mental health program that is designed to support people with a variety of diagnoses both during pregnancy and up to a year postpartum. One example of a program like this is BC Children's '[Reproductive Mental Health Program](https://reproductivementalhealth.ca/)' (hyperlink: <https://reproductivementalhealth.ca/>).

Frazer Health in BC has a '[Seamless Perinatal Health Care Program](https://ridge-meadows.pathwaysbc.ca/programs/2671#:~:text=Provided%20by%20Fraser%20Health,medical%20and%20for%20social%20reasons)' (hyperlink: <https://ridge-meadows.pathwaysbc.ca/programs/2671#:~:text=Provided%20by%20Fraser%20Health,medical%20and%20for%20social%20reasons>) that provides extra medical and/or social support to people during pregnancy. While these and other programs are not designed to support Autistic

people specifically, those with co-occurring depression or anxiety may still find them useful. Programs like these can be helpful in monitoring and supporting you if you need to stop taking certain medications while pregnant. They can also provide access to useful resources and support for both parents once the baby arrives. If you do not have a program like this locally, you can look for the closest program and see what sort of resources they recommend or if they accept referrals for people who live outside of their region.

You may not have the option to choose a specific doctor if you live outside major cities or there is a shortage in your area. In case you can choose, you may want to see if there are medical professionals with a history of supporting neurodivergent people who are pregnant in your area. You may ask other Autistic parents to see if they have a doctor they recommend. If you don't know any Autistic parents in your area, you can also look at reviews online to see if previous patients mention things that make you think the doctor would be supportive (e.g., "takes time to answer my questions").

There are also lists of neurodivergent therapists and practitioners, though these lists are not specific to pregnancy. Many of the people on these lists live outside of Canada, but new names are being added so it is worth checking. Please see the list of resource at the end of this toolkit.

Other new parents, like Jane, choose to only share what their doctor needs to know in order to get the resources or accommodations they want. By saying that she would be unable to speak when overwhelmed, Jane prepared her doctor for that possibility and together they could come up with a plan for how to communicate if it happens. By sharing her anxiety and sensory processing differences, her doctor could be aware of ways to make the birthing experience less stressful for Jane. If you decide that you do not want to share your full autism diagnosis, consider what sort of accommodations you may want and how you can ask for them.

8. How do I best reach out for support during my pregnancy?

As Jane's pregnancy progressed, she wondered how she would get help if needed after she had given birth. What if she was overwhelmed by the demands of a newborn? What if she couldn't tolerate the sleep deprivation, the crying, or the dirty diapers? This was all new to her, and she just didn't know what to expect—and that made her anxious. She did not want to share these concerns with her doctor. What if the doctor thought she was unstable for asking about these issues?

Jane learned that in most Canadian hospitals, labour and delivery and post-partum staff includes social workers among its supportive professionals. Social workers are able to connect new mothers to resources in the community that can help with relationships, financial insecurity, and importantly, with information about issues of post-partum depression.

Jane was unclear what a social worker from the hospital could do for her, and did not know who she should ask if she wanted to see a social worker. She also learned that many municipalities provide support to new parents who experience post-partum depression (PPD), helping new

mothers and their partners understand the symptoms of post-partum depressions, and where to go for help if they suspect PPD. Social workers also connect families to resources if they are struggling with relationship issues or financial insecurity. They may connect parents to programs such as the one in Toronto, called Healthy Babies, Healthy Children. This free home visiting program supports families to have a healthy pregnancy, develop positive relationships with their new babies, and to promote the positive growth and development of babies.

If you are unsure about how to ask for help or bring up these concerns with your doctor, consider using the script below. Feel free to modify/adapt it for your own situation.

Script idea: I feel so much better when I know what to expect. I hear a lot about post-partum depression. Can you help me understand what to do if I begin to feel depressed or anxious? I'm feeling good right now, but I want to be prepared if I have any feelings of being overwhelmed, anxious, or sad. Can you tell me:

- **Would I need a referral?**
- **Is there paperwork I can prepare in advance?**
- **What sorts of supports or programs are available?**
- **Can you provide contact information for the person or program I should access if needed?**

If you are overwhelmed by the volume of information the person is providing, say, "I'll keep this information easily accessible in case I need it. Can I take some time to think about what you've shared and email you if I have more questions?"

Jane's worries about how sleep deprivation may impact her mental health are common among new parents. Hormone fluctuations, healing from pregnancy, and potential difficulties with feeding the baby (whether formula or breastfeeding), can lead parents to feel overwhelmed. This stress can eventually lead to mental health challenges.

Postpartum depression (PPD) describes a major depressive episode that can occur during the pregnancy (pre-partum) or within 4-weeks of delivery. It is estimated to impact up to 23% of all people after they give birth¹⁴, though, as described earlier, this number may be higher for Autistic parents⁴. Common signs of PPD include depressed mood, severe mood swings, frequent crying, and difficulty bonding with the baby¹⁵. Many people with PPD also describe intense feelings of guilt for not feeling connected to their baby¹⁶.

Postpartum anxiety (PPA) can often accompany PPD, but not always¹⁷. PPA is defined as severe anxiety or 'excessive worrying' after becoming a parent. Some anxiety is normal, especially for new parents. However, when someone has PPA, the parent may feel worried all the time that their child is in danger, even if there is not a specific threat. PPA is estimated to impact between 11-21% of new parents¹⁸, but there is not a specific screening tool to diagnose PPA, so the number could be higher. Some examples of PPA may include constantly checking on your baby because you fear they will stop breathing in their sleep, being scared to leave your child alone

for a few minutes with an adult you trust (e.g., your partner), or being afraid to leave the house in case someone tries to take or hurt your child.

It is important to note that both parents can experience PPD or PPA, not just the one who gave birth. It is estimated that roughly 13% of parents who did not give birth also experience depression and/or anxiety just before or after their baby is born^{19,22}. These parents are not often screened for PPD or PPA, meaning that they may not access helpful supports as quickly as parents who gave birth²⁰.

Postpartum psychosis is a severe but much less common postnatal mood disorder that affects just one in 500 or 0.2% of mothers. It can present within the first few days or weeks of delivery²¹. Postpartum psychosis may present as extreme confusion, severe depression, paranoia, delusions, disorganized thoughts, mania, loss of connection with reality, and/or hallucinations. The causes of postpartum psychosis are still being explored at this time, but preliminary research suggests that it may be influenced by hormonal fluctuations, circadian rhythm disruption, immune responses, genetic factors, and/or co-occurring mental health conditions like bipolar disorder or schizophrenia²¹. If a person has postpartum psychosis, it is considered a mental health emergency as, if left untreated, it can lead to devastating effects on the person who gave birth, the baby, and the family.

Each region has their own protocol for connecting new families with resources for mental health supports. It is recommended that you ask your doctor about which supports and resources are available should you decide that you need them. By asking about these resources early on, you may be able to be proactive about connecting with these resources ahead of time and your doctor can help refer you if necessary. Remember, just because you ask about them, it does not mean that you have to use them or that your doctor will judge you for wanting more information.

It can be difficult to know what you are struggling with or if you need help, especially when you are sleep-deprived and just trying to get used to your family's new addition. Also, communicating to a person you don't know very well, even if they are a doctor or social worker, can sometimes be challenging. We suggest that you have a trusted friend, family member, or partner ask you specific questions (below) once a week so you can identify any areas in which you need more support.

A common questionnaire used to assess whether a person may be having challenges with postpartum depression or anxiety is the [Edinburgh Postnatal Depression Scale \(EPDS\)](#). Your medical team may already be using this same screening tool, or another one like it. This tool highlights issues around sadness, guilt, fear, and feelings of being overwhelmed. If any of the answers to the questions indicate a need for additional support, your trusted person can help you schedule an appointment and discuss this with the appropriate person who can help you connect with the support or resources that you need.

Remember, many people struggle with depression and anxiety before and after giving birth. There are lots of different types of support available, whether online or in person. Please see the list of resources at the end of this toolkit for more support options.

9. Planning for the birth

Making a birth plan- what to consider

Jane started planning for her birth within weeks of learning she was pregnant. She determined early on that she would have no pain medication (all the books she read suggested that if she just learned to breathe correctly, she could have a natural childbirth), no family visitors in the room, and no episiotomy. She didn't want her baby to be affected in any way by the drugs needed for an epidural. Besides, she was terrified of the idea of a needle in her spine. Many of the books suggested that rushing the birth process might cause a tear or the need for an episiotomy. She would have a calm birth and would not allow an induction. She read that inductions can cause labour to come hard and fast. Jane was determined to have the perfect birth.

Her doctor told Jane that she could plan for the best but should have a backup plan in case the baby had other ideas. She urged her to keep an open mind to other options. Uncertainty is difficult, but flexibility is important (a mother may not want a caesarean section, but that is not always within the mother's control). She told her that birth in Canada is very safe and is also unpredictable-- mothers who have more than one child often report different experiences with each birth. The doctor was very supportive and reminded her that it is okay if she change her mind and opts for an epidural, or if they wanted a drug-free vaginal birth and had a caesarean section. Whatever they decide is right for them once they are in labour and then labour progresses is the right thing to do. The mother is in control of what happens unless an emergency caesarean is required. It is best to understand and be aware of what happens in the event of a C-section. Uncertainty about the process will just heighten anxiety, but information beforehand and during the procedure will help to better tolerate the situation.

Jane liked that idea. She had to admit that she was terrified every time she thought about this watermelon-sized baby coming out of her vagina. She didn't know for sure she could endure the pain or discomfort of contractions, either. They were a completely unknown entity. She paid close attention when some friends and co-workers told her that epidurals take all the pain away. Some even said the epidural needle did not hurt. She felt that focusing on her birth plan helped to ground her and ease her anxiety about her delivery and the uncertainty it carried.

Many parents create a birth plan to help express their desires about how their birthing experience will go. As Jane's doctor expressed above, not all births can go according to this birthing plan as emergency situations can arise. If the baby is in distress or there are immediate health concerns for the person giving birth, the medical team may make the quick decision to

have an emergency c-section. Even if there are no emergencies during the birth, the person giving birth may change their mind about pain medications like epidurals once they experience the pain of contractions.

If you decide to have a birth plan, you can share that with your doctor ahead of time. Many hospitals have a standard form they use where you can express your desires for both the birth and for immediately after your child is born. The hospital's birth plan will likely ask you questions about how you would like the doctors to help manage your pain. You will also be asked about who you want in the room with you (e.g., your partner, family member, midwife, doula, etc.), and who will be cutting the umbilical cord, and if you intend to breastfeed or bottle feed.

One thing to keep in mind is that in certain hospitals, the use of a midwife may be impacted if you choose an epidural. When this is the case, some hospital policies require the midwife to transfer care to the obstetrician on call. If this is a concern for you, be sure to check both with your midwife and the hospital you plan to give birth at to see what their rules are around this possibility.

Some things you may want to decide upon after your baby is born, and it is important to be flexible with these plans as well. The birth giver's plan may be to give the baby its first bath, but if they are too sore to stand, they can observe while their partner does the bath. Keep in mind that religious and cultural preferences can be affirmed and prioritized in your post-birth plan.

You may want to print off multiple copies of your birth plan and keep it in the bag you bring to the hospital (commonly referred to as a 'go-bag'). Below are some additional suggestions for what you can pack in the 'go-bag'.

Packing your 'Go-Bag': What to consider bringing to the hospital with you

Each province and territory in Canada are responsible for its own healthcare, so ask your hospital what supplies your responsibility are, and then you can pack your bags accordingly.

- Health card and any additional insurance information
- Cell phone and an extra-long charger
- Eyeglasses or contacts/solution
- Daily prescription medications
- Warm, non-skid socks or warm socks and slippers (for walking in the hall during labour and after delivery)
- A warm bathrobe
- Lip balm (your lips get very dry from breathing through contractions and from dry hospital air.

- Lozenges or mints for dry mouth—sugar-free is best
- Headband
- Sanitary pads
- Snacks
- Maternity bras and nursing pads. For Autistic people with tactile sensitivities, try wider straps.
- Toiletries like toothpaste, toothbrush, deodorant, face wash, shampoo
- Lightweight sleepwear (hospitals can be hot).
- Clothes for returning home. Maternity clothing works well. Your uterus takes several weeks to shrink back down in size.
- Your own comfy pillow.
- Your own comfy blanket
- Maternity underwear—something you don't mind throwing away.
- A breastfeeding pillow
- Bring shoes you can easily put on and off, like Crocs. Your feet may be too swollen with fluids to wear regular shoes.
- If you've made a detailed birth plan, print it out with the main points highlighted. Ask for one to go in your chart, tape one up in your room, and give the other to your labour nurse.
- Bring your own comfy bath towel. Hospital towels are often thin and scratchy.
- Nipple cream

Baby bag checklist

- Approved baby car seat installed
- Coming home outfit
- Newborn diapers
- Warm blankets
- Pediatrician checklist

Partner checklist

- Snacks
- Cell phone and charger for pictures
- Camera with extra batteries if you prefer not to use your phone camera
- Reading material
- Toiletries—shampoo, face wash, wash cloth, deodorant, toothbrush, toothpaste
- A comfy blanket and pillow.
- Clean clothes
- Pajamas
- Any daily prescriptions

10. The Birth

Jane's pregnancy went quite smoothly well into the end of her third trimester. By then, she was quite fed up with random people rubbing her tummy, giving unwanted advice, and scaring her with their birth stories.

On the first day of her 40th week (and her first week of her maternity leave), her mucus plug dislodged and had a little bit of blood in it. After an initial wash of fear, Jane was excited to realize labour would begin within three days. That same night, Jane woke soaked in what she thought was urine. She woke her partner so they could change the sheet, but as she stood, a rush of very warm liquid streamed down her leg. Her water had broken, and it was time to go to the hospital. Jane got changed and into the car as her partner loaded up the hospital bags. On the way to the hospital—a 30-minute drive—she began to have contractions. They were 10 minutes apart and lasted about 50 seconds. The intensity of the contractions startled Jane. It was a tightening across her back and stomach as her body worked to dilate her cervix and move her baby down. It was so strong that Jane wondered if the birth might be close. She was eager to get to the hospital.

Jane and her partner went to the labour and delivery ward and were directed into a room. She got changed into a comfortable nightgown, socks and slippers. She had all the right supplies and was ready to tackle labour. Once her labour nurse was finished asking questions and examining her (she was already 3 cm dilated), she left and returned with supplies to start an IV. Jane's doctor told her this is something she routinely did to keep her patients hydrated and to allow for easy interventions should an emergency arise. With the IV installed, Jane and her partner began to walk the halls, with Jane stopping periodically as her contractions strengthened and got closer together. After about an hour, Jane was unable to walk through the pain any longer, and they returned to her room. She climbed on the bed, and found the sheets felt like sandpaper. Her contractions were getting closer together and very intense. Her partner called the nurse who checked her again. Jane was now only 3.5 cm dilated. Jane said the pain was so bad she thought something was wrong. The nurse assured her she was doing well and so was the baby. Jane was now frightened. She knew that the contractions were going to get longer in duration and closer together. She could barely manage herself now, as it seemed a new contraction was starting very soon after one ended. Jane spoke with her partner. She wanted to have an epidural. No matter how painful she feared it would be, it would only last a few moments and then she would be pain-free. Her partner reminded her she is in charge and whatever she decides is the right decision. Jane asked for an epidural.

The nurse contacted the doctor, who then ordered an epidural. The anaesthesiologist arrived about an hour later. It seemed like an eternity to Jane. The nurse checked Jane again and she was 4 cm dilated. Jane was relieved that her cervix was more dilated, as she read that 'cervical recoil' can actually cause the cervix becomes less dilated before it softens and continues dilating again. Jane couldn't tolerate having a pelvic exam and was getting very irritable. The experiences of being touched along with the sound of everyone talking in the room and the

rough bedsheets were too much. She could think of nothing but her sensory overwhelm between contractions. The anaesthesiologist asked her to arch her back and stay still. She was sitting up. He used a cold wipe—an antiseptic—to clean her back. He then injected a small area on her back with a local anaesthetic to numb the area. Jane felt nothing but minor pressure on her back as the doctor did his work. That work included inserting a small catheter into the needle. The catheter is taped into place and medication can be given continuously or as prescribed by the doctor.

When it was done, Jane could hardly believe it. She felt almost no pain at all after having the epidural installed. The worst thing was the contraction that happened as the doctor was working, because she had to stay completely still. She had two more contractions and then...nothing. She couldn't feel any pain at all. The epidural literally eliminated all pain from the contractions.

Two hours later, she delivered a healthy baby girl weighing 8 lbs, 8 oz. Her doctor said she was going to tear if she didn't give her an episiotomy, so Jane agreed to the procedure. Jane did not feel the incision, nor the stitches that came after the birth. The two things she had been most fearful of were things she had to face. Neither were as horrible as she thought they would be. After the birth was over, nursing staff massaged her belly and the afterbirth was delivered. Nurses then cleaned her and her baby, then left the new family alone. Jane was elated and still completely pain-free. Suddenly, she started to tremble. She was shaking so violently her partner called the nurse in. The nurse said post-partum shaking is very common and is harmless. The mother's arms and legs shake in an effort to get warm after her body had moved its blood to the woman's core. The nurse gave Jane a warmed-up flannel blanket and she felt much better.

Over the next 24 hours, medical staff seemed to come into Jane's room constantly to check on her. She felt that special bonding time with her new family was being disturbed as they lifted the blanket and checked her menstrual pad, her stitches, felt her uterus and checked her vitals. She couldn't wait to get out of there and go home. Every hour or so, baby Emma would cry, and her partner would bring her to Jane to breastfeed. The baby had trouble latching on at first, so a nurse came in, picked up Jane's breast with two fingers just above the nipple, and pushed the nipple far into the baby's mouth. Emma happily latched on. Jane was shocked to have someone come in and grab her breast as if it was an inanimate object. She was more shocked at the suction Emma had as she suckled with the strength of a vacuum. Jane had a hard time tolerating the suction at first and wondered if she'd be able to keep this up. Twelve hours later, Jane felt like a pro as Emma latched well each time she nursed.

Jane was uncomfortable at the number of people who would examine and touch her body without warning. It was upsetting to feel like she had no control over who touched which private areas and when. While you can include a wish for people to warn you before touching your body in your birth plan, not all medical professionals will have read it, especially once you have already delivered your baby. Some parents may choose to post notes by their bedside requesting to be warned before being touched, even if they are sleeping. If this is something

you are concerned about, please bring it up with your doctor to see if they have suggestions on how to avoid being surprised by someone touching your body without warning.

Jane was fortunately able to breastfeed her baby without much difficulty. In some cases, however, you may need the support of a lactation specialist. A lactation specialist is a certified health professional who can provide guidance with issues like breastfeeding positions, sore nipples, or increasing milk supply. Some hospitals have lactation specialists who check in with each new parent who wishes to breastfeed, while other lactation specialists work via private practice. Do not be surprised if your baby wants to feed every 45 minutes in the first few weeks or longer. Growing takes energy! Also, it is common for babies to lose up to 10% of their birthweight in the few days following being born. If your baby is nursing regularly, do not doubt your ability to breastfeed. **Most babies are back to their birth weight by the time they are two weeks old.**

11. Postpartum at home

Jane went home after 30 hours in the hospital. She felt remarkably good, but tired. She couldn't wait to get some sleep, as she is a person whose mood is really affected by sleep disturbances. For the first four days, she was the only one who could feed the baby, as her milk had not yet come in and the baby was only getting colostrum, a thick, sticky nutrient rich milk. When her milk arrived, her breasts were huge and hard, and she eagerly used the breast pump to relieve the pressure. By nighttime, she had collected enough extra milk for three feeds. Her partner did those feeds and let her sleep for three consecutive hours. The sleep deprivation was the most difficult part of the birth and post-partum period. Her mom, her sister, and her aunt would take turns coming over to help, and the most appreciated help was letting her nap. Her mom knew that the sleep changes would be hard on Jane. As a child, Jane used to cry when she was tired, and as an adult, she didn't feel much different, but the distress came out as irritability. Jane also found it a challenge to drink enough now that she was nursing. She continued to follow the doctor's orders, though. Her pediatrician told her she needed to get the equivalent of 16 cups of water a day. Jane made a schedule to ensure she kept herself hydrated. She was also advised she had to eat more as a nursing mother. Given her history of an eating disorder, this took commitment from Jane, who did careful menu planning and scheduling to make sure to take in the necessary calories.

Jane was very surprised to know that she would still look pregnant for weeks after she gave birth. If she didn't have to care for a baby, she would have started dieting to hurry up the process. She didn't recognize her body with its large breasts and hanging distended belly with crepey skin. Six weeks later, she was back into her pre-pregnancy clothing, and was starting to see herself again when she looked in the mirror.

Jane's partner and family were able to provide her with much-needed support as she settled into the new routine of being a parent. Sleep deprivation is one of the most challenging parts of

having an infant, especially for those who already struggle with getting enough sleep. Poor sleep is also closely tied with developing PPD/PPA²³, so if that is a concern for you it can help to have a support structure in place before giving birth. Breast pumps can help you prepare extra bottles to allow you to have consecutive hours of sleep while someone else feeds the baby. If you are worried about being able to manage with little sleep once you bring your baby home, consider looking at your resources and deciding what sort of extra help you can bring in.

While this is only an option if your finances will allow, it can be helpful to pay for the help you need. If you do not have a partner and family or friends are too far to help, consider paying for a postpartum doula to help take care of the baby while you sleep. If you are concerned about being able to stay on top of household chores like laundry (babies go through a lot of it!) or cleaning, you may consider hiring a housekeeper to come by once or twice a week. If getting to the grocery store is too difficult, consider getting groceries delivered. You and your partner do not have to do everything by yourselves!

12. Conclusion:

Pregnancy can be an exciting and scary time for any new parent. For the Autistic person giving birth, the experience can be more exciting than scary with a little preplanning and careful consideration of your autism-specific needs and strengths. The more knowledge you have about what to expect next, the more prepared you can feel for any procedures or appointments. The more informed you are about how to take care of yourself, the more in control and the less anxious you may feel.

Autistic parents are encouraged to communicate what they need in order to have the best experience possible. Let your health care provider know your preferred ways of communication. For instance, do you need to provide questions ahead of time via a list? Will you ask to use email to pose questions? Will your partner help you to advocate for your needs?

Sharing your sensory needs can also reduce anxiety and help to make the experience more pleasant. Wear your ear protection with pride. Use sunglasses in the waiting room if you need them, and in the delivery room if you need them with the bright lights. Instruct medical staff to advise you beforehand if they need to touch you. All of your preferences can be documented, and your partner can be your advocate to stay ahead of any new staff who need to be informed.

Pregnancy can be a wonderful experience. The increased awareness of neurodivergent patients means the medical community is more open than ever to supporting the needs of Autistic people. One thing we can do as Autistic people is to find a way to communicate our needs and to ask for help accessing community resources if we need it. We can do these things ourselves or lean on the allies and advocates in our lives. You'll find that medical staff are more open than ever to hearing (or reading) what we have to say, and to finding ways to make our

contacts with them more positive experiences. Wishing all of you embarking on this journey of parenthood the love and support of your Autism community. You can do this. You are doing it!

13. Additional Resources:

Sensory Processing Differences Toolkit

- Hyperlink: <https://aidecanada.ca/resources/learn/sensory-regulation/sensory-processing-differences-toolkit>

Ready to Learn Interoception Kit

- Hyperlink: <https://www.education.sa.gov.au/sites/default/files/ready-to-learn-interoception-kit.pdf>

Interoception 301 Activity Guide

- Hyperlink: <https://www.education.sa.gov.au/sites/default/files/interoception-301-activity-guide.pdf>

Understanding what is happening inside your body: Interoceptive training for all ages

- Hyperlink: <https://aidecanada.ca/resources/learn/health/understanding-what-is-happening-inside-your-body-interoceptive-training-for-all-ages>

Your Guide to a Healthy Pregnancy

- Hyperlink: <https://www.canada.ca/en/public-health/services/health-promotion/healthy-pregnancy/healthy-pregnancy-guide.html>

NeurodivergentPractitioners.org

- Hyperlink: <https://neurodivergentpractitioners.org/>

*Unfortunately, it looks like there may be only one listing in Canada currently. Check back regularly for updates.

Neurodivergent Therapists

- Hyperlink: <https://ndtherapists.com/canada/>

Autistic Doctors International:

- Hyperlink: <https://autisticdoctorsinternational.com/>

Postpartum Support International:

- Hyperlink: <https://www.postpartum.net/get-help/locations/>

- PSI volunteers will help connect parents and families to local providers who are trained to treat perinatal mood and anxiety disorders.

- PSI Helpline: Call or text 800-944-4773 (for Spanish, text 1-971-203-7773)

Canada specific postpartum resources:

- Hyperlink: <https://www.postpartum.net/canada/>

Additional Mental Health Resources in Canada:

- Hyperlink: <https://www.canada.ca/en/public-health/services/mental-health-services/mental-health-get-help.html>

Canadian Mental Health Association:

- Hyperlink: <https://cmha.ca/find-help/>

The Canadian Association of Cognitive and Behavioural Therapies - CACBT:

- Hyperlink: <https://cacbt.ca/en/certification/find-a-certified-therapist/>

TeleCBT.ca

- Hyperlink: [Telecbt.ca](https://telecbt.ca)

Autism-Focused Resources Autistic Self Advocacy Network:

- Hyperlink: <https://autisticadvocacy.org/>

- Resources page: <https://autisticadvocacy.org/resources/>

Autism Women & Non-Binary Network:

- Hyperlink: <https://awnnetwork.org/>

- Resources page: <https://awnnetwork.org/resource-library/>

Global and Regional Autism Spectrum Partnership:

- Hyperlink: <https://grasp.org/>

- Resources page: <https://grasp.org/resources/>

AIDE Canada:

- Hyperlink: <https://aidecanada.ca>

- Resources page: <https://aidecanada.ca/learn>

- Peer Advice Video Landing Page: <https://aidecanada.ca/connect/peer-advice-landing-page>

14. Suggested Reading:

Mayo Clinic Guide to a Healthy Pregnancy, 2nd Edition by M. J. Wick

Women and girls with autism spectrum disorder: Understanding life experiences from early childhood to old age by Autistic author and self-advocate Sarah Hendrickx ([available in the AIDE Canada library](#))

Spectrum Women: Autism and Parenting by Renata Jurkevithz, with contributions by M. Campbell, L. Morgan, and B. Cook about their experiences of pregnancy as Autistic parents ([available in the AIDE Canada library](#))

15. References

1. Mitra, M., Parish, S. L., Clements, K. M., Cui, X., & Diop, H. (2015). Pregnancy outcomes among women with intellectual and developmental disabilities. *American journal of preventive medicine*, 48(3), 300-308.
2. Sundelin, H. E., Stephansson, O., Hultman, C. M., & Ludvigsson, J. F. (2018). Pregnancy outcomes in women with autism: a nationwide population-based cohort study. *Clinical epidemiology*, 10, 1817–1826. <https://doi.org/10.2147/CLEP.S176910>
3. Rogers, C., Lepherd, L., Ganguly, R., & Jacob-Rogers, S. (2017). Perinatal issues for women with high functioning autism spectrum disorder. *Women and Birth*, 30(2), e89-e95.
4. McDonnell, C. G., & DeLucia, E. A. (2021). Pregnancy and Parenthood Among Autistic Adults: Implications for Advancing Maternal Health and Parental Well-Being. *Autism in Adulthood*, 3(1), 100-115.
5. Samuel, P., Yew, R. Y., Hooley, M., Hickey, M., & Stokes, M. A. (2022). Sensory challenges experienced by autistic women during pregnancy and childbirth: A systematic review. *Archives of Gynecology and Obstetrics*, 305(2), 299-311.
6. Hampton, S., Allison, C., Baron-Cohen, S., & Holt, R. (2022). Autistic People’s Perinatal Experiences I: A Survey of Pregnancy Experiences. *Journal of Autism and Developmental Disorders*, 1-13.
7. American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC
8. DuBois, D., Lymer, E., Gibson, B. E., Desarkar, P., & Nalder, E. (2017). Assessing sensory processing dysfunction in adults and adolescents with autism spectrum disorder: a scoping review. *Brain sciences*, 7(8), 108.
9. Little, L. M., Dean, E., Tomchek, S., & Dunn, W. (2018). Sensory processing patterns in autism, attention deficit hyperactivity disorder, and typical development. *Physical & occupational therapy in pediatrics*, 38(3), 243-254.
10. DuBois, D., Ameis, S. H., Lai, M. C., Casanova, M. F., & Desarkar, P. (2016). Interoception in autism spectrum disorder: A review. *International journal of developmental neuroscience*, 52, 104-111.
11. Palser, E. R., Fotopoulou, A., Pellicano, E., & Kilner, J. M. (2018). The link between interoceptive processing and anxiety in children diagnosed with autism spectrum disorder: Extending adult findings into a developmental sample. *Biological Psychology*, 136, 13-21.
12. Goodall, E. (2020). Interoception as a proactive tool to decrease challenging behaviour. *Scan: The Journal for Educators*, 39(1), 20-24.
13. Quenby, S., Gallos, I. D., Dhillon-Smith, R. K., Podesek, M., Stephenson, M. D., Fisher, J., ... & Coomarasamy, A. (2021). Miscarriage matters: the epidemiological, physical,

psychological, and economic costs of early pregnancy loss. *The Lancet*, 397(10285), 1658-1667.

14. Hutchens, B. F., & Kearney, J. (2020). Risk factors for postpartum depression: an umbrella review. *Journal of midwifery & women's health*, 65(1), 96-108.
15. Statistics Canada Maternal mental health in Canada, 2018/2019. 2019, June 24. <https://www150.statcan.gc.ca/n1/daily-quotidien/190624/dq190624b-eng.htm>
16. Putnick, D. L., Sundaram, R., Bell, E. M., Ghassabian, A., Goldstein, R. B., Robinson, S. L., ... & Yeung, E. (2020). Trajectories of maternal postpartum depressive symptoms. *Pediatrics*, 146(5)
17. Newman, D. L. M., Boyarsky, M., & Mayo, D. (2022). Postpartum depression. *JAAPA*, 35(4), 54-55.
18. Li, H. (2022). Maternal-Infant Attachment and its Relationships with Postpartum Depression, Anxiety, Affective Instability, Stress, and Social Support in a Canadian Community Sample. *Psychiatric Quarterly*, 1-14.
19. Zappas, M. P., Becker, K., & Walton-Moss, B. (2021). Postpartum anxiety. *The Journal for Nurse Practitioners*, 17(1), 60-64.
20. Da Costa, D., Danieli, C., Abrahamowicz, M., Dasgupta, K., Sewitch, M., Lowensteyn, I., & Zelkowitz, P. (2019). A prospective study of postnatal depressive symptoms and associated risk factors in first-time fathers. *Journal of affective disorders*, 249, 371-377
21. Perry, A., Gordon-Smith, K., Jones, L., & Jones, I. (2021). Phenomenology, epidemiology and aetiology of postpartum psychosis: a review. *Brain sciences*, 11(1), 47.
22. Eddy, B., Poll, V., Whiting, J., & Clevesy, M. (2019). Forgotten fathers: Postpartum depression in men. *Journal of Family Issues*, 40(8), 1001-1017
23. Park, E.M., Meltzer-Brody, S. & Stickgold, R. Poor sleep maintenance and subjective sleep quality are associated with postpartum maternal depression symptom severity. *Arch Womens Ment Health* 16, 539–547 (2013).
<https://doi.org/10.1007/s00737-013-0356-9>