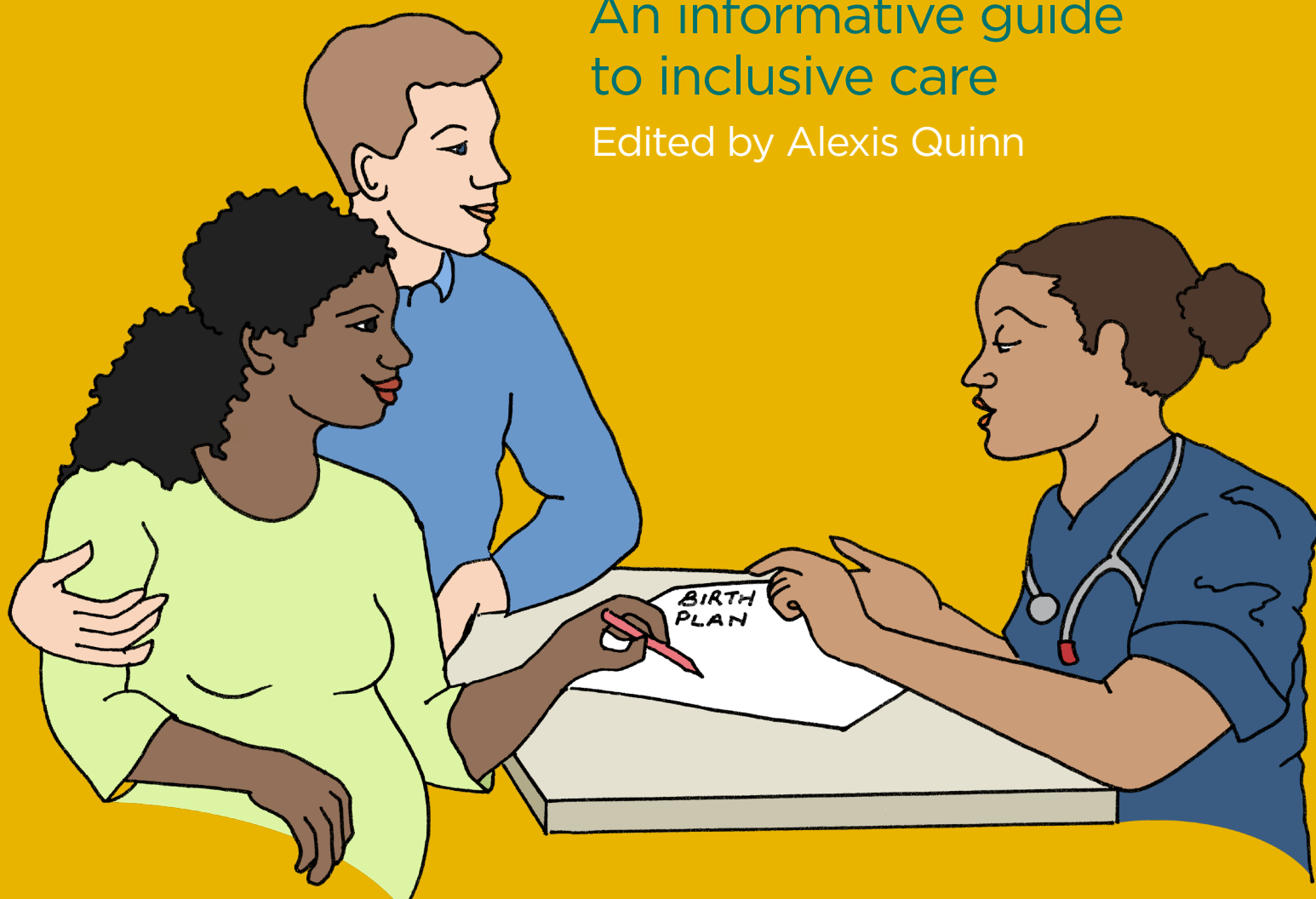




Supporting autistic pregnant women and birthing people

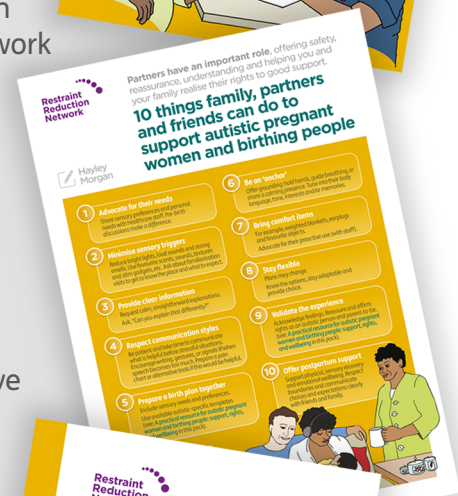
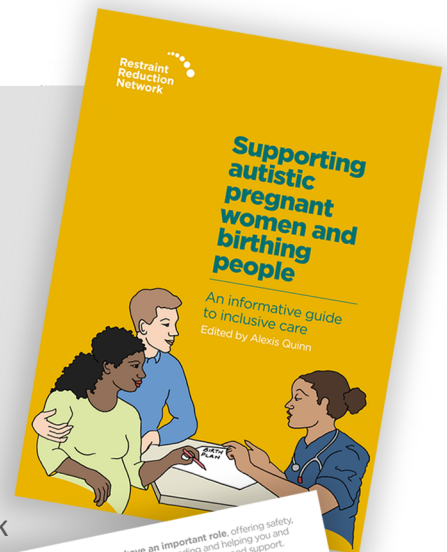
An informative guide
to inclusive care

Edited by Alexis Quinn



These resources were coproduced by people with lived experience and designed for autistic pregnant women and birthing people, and people supporting them, to get rights-respecting care. There is a:

- **Information guide** designed specifically for professionals supporting autistic pregnant women and birthing people to get rights respecting care, although autistic people and their support network will find the information helpful too.
- **Single page summary sheet/poster** which gives a list of 10 key points that family, partners and friends can do to support autistic pregnant women and birthing people.
- **Practical and interactive resource** which aims to give practical, supportive and rights-respecting information to help autistic pregnant women and birthing people feel confident and informed.
- **Breastfeeding resource** designed with kindness and respect, to help autistic pregnant women and birthing people feel supported, empowered and confident in their choices to nurture their baby.



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Please note that this document does not, and is not intended to, constitute legal advice. The RRN strives to provide accurate, well-researched information that is helpful to practitioners, professionals and people with lived experience.

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Authors of this resource and additional resources

Alexis Quinn – Autistic mother, author of *Autistic and Expecting – practical support for parents-to-be and health and social care practitioners* (featuring on The Reading Agency list 2025).

Aimee Grant – Autistic Associate Professor at Swansea University and author of *The Autism Friendly Guide to Pregnancy, Birth and the Fourth Trimester*.

Claire Malcolm – Mother of autistic children, Lecturer in Politics (The Open University), Anti-Racism Consultant, and co-author of *Mothering at the Margins: Black Mothers Raising Autistic Children in the UK*.

Elena Sheldon – Psychologist (perinatal mental health), Visiting Research Associate at The University of Sheffield.

Ella Jackson – Autistic NHS Infant Feeding Specialist Midwife, IBCLC, Tongue-tie Practitioner.

Hayley Morgan – Autistic mother, PhD candidate and co-author of *Supporting Autistic People Through Pregnancy and Childbirth*.

Karen Henry – Autistic mother, Midwife, Midwifery Lecturer and co-author of *Supporting Autistic People Through Pregnancy and Childbirth*.

Mel Green – Lecturer, researcher, and mother of two, one autistic and non-speaking, co-author of *Mothering at the Margins: Black Mothers Raising Autistic Children in the UK*.

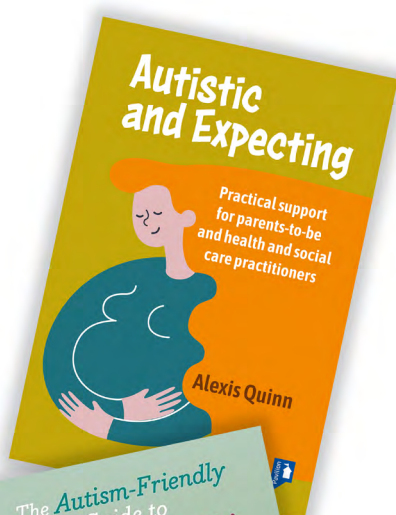
Sara King – Autistic mother, PhD candidate, autistic peer group lead and mentor.

Rebecca Brione – Expert in Ethics and Human Rights in Pregnancy and Birth.

Stacey-George Hemes – Registered Midwife and Maternity Autism Research Group (MARG) Secretary.

Vanessa Garrity – Mental Health Nurse, Perinatal Mental Health Specialist, Associate Director of Clinical Quality and Regulation with lived experience of neurodivergence.

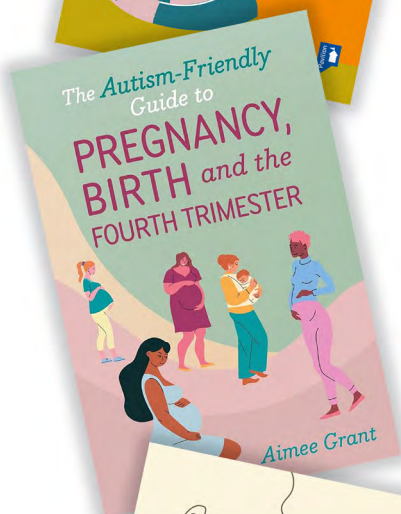




Autistic and Expecting: Practical support for parents to be and health and social care practitioners

Alexis Quinn

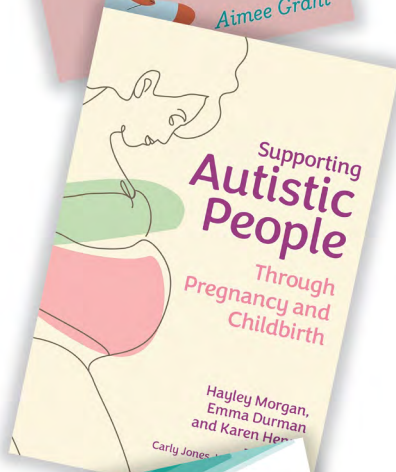
A unique and practical book on managing autistic pregnancy, childbirth and the post-natal period for autistic parents and for the health and social care practitioners who may support them. A practical, insightful and solution-focused guide, providing the information, resources and confidence autistic parents need to advocate for themselves. **(Featuring on The Reading Agency list 2025).**



The Autism-Friendly Guide to Pregnancy, Birth and the Fourth Trimester

Aimee Grant

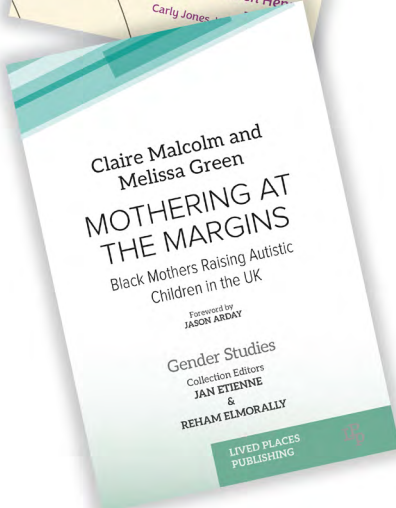
An accessible guide to navigating every step of pregnancy, birth and the fourth trimester for autistic people. The dip-in-dip-out format provides you with an easy-to-navigate exploration into sensory overwhelm, managing demanding medical appointments, navigating being a new parent and everything in between. Links to YouTube videos and downloadable materials help support you in navigating your journey.



Supporting Autistic People Through Pregnancy and Childbirth

Hayley Morgan, Emma Durman, Karen Henry

This comprehensive and accessible guide is for every birthing and health professional looking to improve their care during pregnancy, birth, and aftercare for autistic women. This book takes an intersectional, feminist approach and covers modern birth practices and autism as a diagnosis. The impact of cultural differences, underdiagnoses, stigma, and stereotypes amongst ethnic minorities is also included.



Mothering at the Margins. Black Mothers Raising Autistic Children in the UK

Claire Malcolm, Melissa Green

Drawing from personal experience of raising autistic children, as well as a hybridised theoretical framework of Black Feminisms, Critical Race Theory, and Critical Disability Studies, this pioneering text offers an unparalleled lens into the intersecting spheres of race, gender, and disability. Through individual testimonials, critical assessments of current practice, and actionable solutions, the authors compel readers to confront and dismantle the triad of oppression faced by these mothers.

Introduction

Alexis Quinn

Welcome to this information guide designed specifically for professionals supporting autistic women and birthing people to get rights-respecting care, although autistic people and their support network will likely find the information in here helpful too.

Autism is a neurodevelopmental condition that influences how people perceive and interact with the world and affects each person uniquely. Typically, autistic people experience heightened sensitivities, prefer sameness, and use a communication style that may differ from non-autistic people. Our resources aim to ensure that any autistic journey through pregnancy and into parenthood is as well-informed as possible. As such, autistic academics, autistic maternity experts, and autistic parents have created this information guide.

Each autistic person will experience autism, pregnancy and childbirth differently. That said, professionals and autistic people can plan for many aspects of these sometimes scary and unfamiliar events. In the following pages you will find a comprehensive array of resources that focus on crucial aspects of maternity care, including how to create and identify neuro-affirming environments, sensory and communication support, tailored birth planning, ethical-legals insights, supporting lactation, mental health, and much more.

We hope, that with the extra knowledge from this guide, everyone can approach autistic maternity with confidence, advocating for what matters most.



Language matters!

Alexis Quinn

This resource has made some language choices that we hope affirms identity and inclusivity, creating a more compassionate and understanding space for autistic people navigating pregnancy and parenting.

We use identity first language – **‘autistic person’** – based on research that has shown autistic people prefer to understand autism as an integral part of themselves which cannot be separated from their experiencing (Bury et al., 2022; Botha et al., 2021).

Additionally, we have chosen to refer to the person carrying the baby as **‘pregnant women and birthing people’**, recognising that not all people who become pregnant identify as women (Moxley, 2023). This language respects the diversity of gender identities, ensuring everyone feels represented throughout their pregnancy journey.



Rights in birth: an overview



Rebecca Brione

The law protects the rights of pregnant and birthing people to make informed decisions that are right for them about what care they receive. This section gives an overview of those rights and where to find out more.

Key rights in birth: an overview



All pregnant women and birthing people have the right to receive balanced information about the risks and benefits of possible care and interventions.

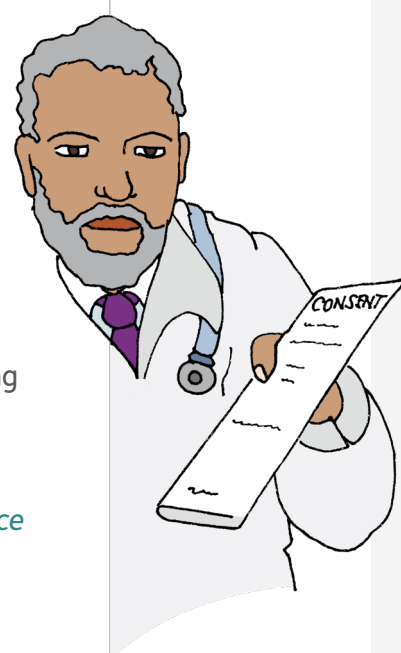
They have the right to information about ‘material risks’: that means both risks that a reasonable person would be likely to consider significant, and risks that the *particular* patient considers significant.

- Given autistic communication needs, it is important to ask questions about how information is best conveyed and received and allow time for the person to express what is important to them.
- It is important to remember that non-clinical information may be of great importance to the person, e.g., where care will be offered if you work in an organisation that has multiple sites.



The law gives people a (near) absolute right to refuse care that they do not want, even if you think they are making an unwise decision. The only exception is when someone is found to lack mental capacity to make the decision in question (see section on mental capacity, page 14).

- Autistic people may find it hard to say ‘no’ because many have a history of being forced to comply with things they don’t like (Dückert et al., 2023; Greenwood et al., 2023; Piper and Charlton, 2025). You need to be confident that if a person says, ‘yes’, they really do mean ‘yes’.
- It is unlawful to give care or perform interventions without positive consent, except in very limited circumstances (for example, in an emergency when the person is unconscious, unlikely to regain consciousness in time to give consent, and the care is necessary to prevent a significant worsening of the situation).
- It is important to talk to autistic women and birthing people about how they may wish to communicate their decisions during perinatal care, labour and early parenting, and to find out if they would like any communication support (see [A practical resource for autistic pregnant women and birthing people: support, rights, and wellbeing](#) in this series).
- You must not put pressure on someone to accept the care you recommend. If you do, their consent may not be valid.
- It is unlawful to override someone’s decision because you think it is in the best interests of their foetus.
- If a person changes their mind during an intervention and withdraws consent, you must stop as soon as possible.
- Maternity units are not allowed to have blanket policies which require women and birthing people to consent to certain interventions (e.g., vaginal examinations) or to be admitted for care. People’s care needs to be assessed on a case-by-case basis, (e.g., using different methods to assess progress of labour).



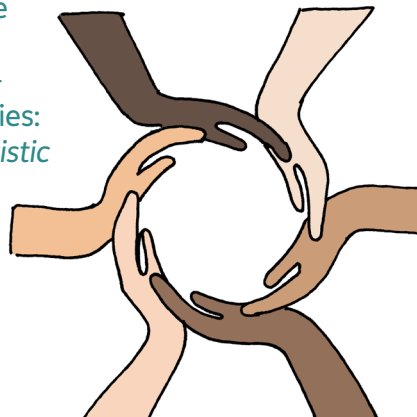


The law in the United Kingdom is clear that the foetus does not have any rights until it is born.



The law protects autistic women and birthing people from discrimination on the grounds of personal characteristics, including disability, race, age and gender. You must therefore make reasonable adjustments so that your autistic patients are not disadvantaged when they access care.

- Reasonable adjustments are personal to the individual. Every autistic person will have individual needs. Reasonable adjustments might include support with communication, changes to rooms to accommodate sensory needs (e.g., lighting levels), or familiarisation tours of the unit.
(See section on reasonable adjustments, page 19.
Then, refer to the accompanying resource in this series: *A practical resource for autistic pregnant women and birthing people: support, rights, and wellbeing.* Provide support to fill the form in if needed.)





The law protects autistic women and birthing people's rights to choose how and where they give birth.

- It is especially important for autistic people to choose an environment in which they feel safe to give birth (Hampton et al., 2022a, 2022b; Quinn, 2021).
- Consider any reasonable adjustments to birthing environments that will meet the person's needs (Grant et al., 2025; Morgan et al. 2024; Quinn, 2021).
- Nobody can be compelled to give birth in hospital if they do not want to. A person who wants a home birth should be supported to access this, even if they are deemed to be 'high risk'. If you have concerns about safety, you can explain these clearly and neutrally, but you must not pressure someone to give birth in hospital. Choosing a home birth against advice is not grounds for a social services referral. See: <https://birthrights.org.uk/factsheets/choice-of-place-of-birth/>
- There is not an absolute right to give birth in a midwife-led unit. However, units are not permitted to have blanket rules excluding people on the grounds of broad characteristics, such as age, BMI, being autistic or other health conditions. If a person wishes to use a midwife-led unit, this should be supported, unless you can show there are risks *specific to that person's circumstance* which the centre cannot safely manage.





Autistic women and birthing people have a right to language support if necessary (see section on reasonable adjustments, page 19, and section on supporting autistic people within perinatal mental health services, page 36). Interpretation should be provided at every appointment if it is needed.



Human Rights
Act 1998



Equality
Act 2010

These rights are grounded in different parts of the law. Relevant parts include the Human Rights Act 1998, the Equality Act 2010, and the common law (decisions made by the courts). To find out more, see: birthrights.org.uk/factsheets/human-rights-in-maternity-care.

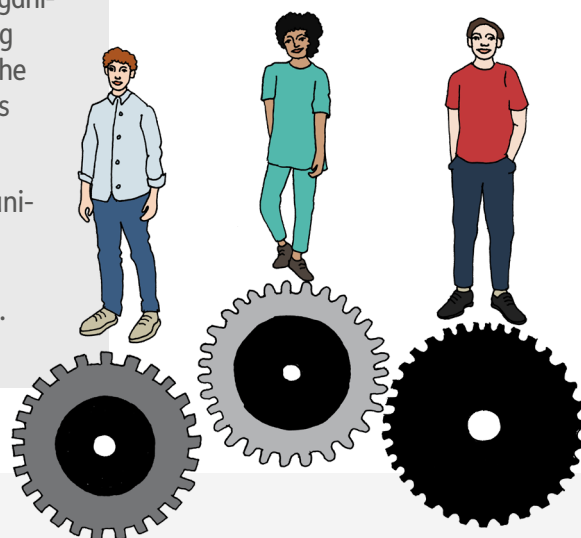
It is everyone's job to make sure that autistic people receive rights-respecting care.

It is your job to make sure that you always have consent before doing any examination or intervention. It is also your responsibility to make sure that that consent is informed.

But: it is not only up to you. The organisation that you work for (e.g., your Trust or Health Board) has the responsibility to make sure that the organisation as a whole is providing rights-respecting care. For example, there is a responsibility on the organisation to make reasonable adjustments where they are needed.

Similarly, there is a responsibility on the organisation (as a whole), to make sure there are appropriate language resources available for autistic people that they can understand.

**Remember!
Human rights
are there to
help health
care staff/
professionals
too.**





Mental Capacity Act 2005

There is no reason to think a person who is autistic will lack capacity.

Similarly, there is no reason to think a person with a mental health condition will lack capacity.

Mental capacity

The law about mental capacity is set out in the Mental Capacity Act 2005, supported by the Mental Capacity Act Code of Practice. These set out under what circumstances a person may be deemed unable to make a decision about their care, and what happens in these circumstances. This section gives a headline overview only: for more information, see: gov.uk/government/publications/mental-capacity-act-code-of-practice

The law presumes that all adults have capacity to make their own decisions. No one should be treated as lacking capacity based on assumptions (e.g., their appearance, or what might happen during labour). Neither should anyone be assumed to lack capacity because they make a decision other people think is unwise.

A person is deemed to lack mental capacity only if they are unable to make a specific decision because of a temporary or permanent impairment or disturbance in the functioning of the mind or brain. Making a decision means understanding the relevant information, retaining it, weighing it to make a decision, and communicating the decision.

If you have concerns about a person's ability to make a decision, you need to provide them with support. It is particularly important to discuss possible support ahead of time if a person finds it difficult to process information or communicate in certain situations, for example when they are in pain. This is why we have created, *A practical resource for autistic pregnant women and birthing people: support, rights, and wellbeing* to assist you in supporting your autistic clients.

If a person is found to lack capacity to make a decision, even with appropriate support, then a decision can be made in their best interests. This should consider their expressed wishes and views. A best interests decision can be made by the treating clinician. Occasionally, best interests decisions are made by the Court.

Autistic self-identification

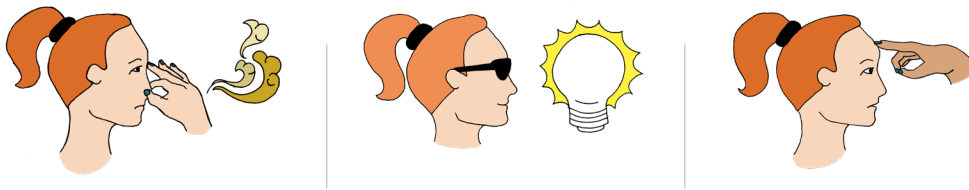
Reasons to provide necessary support

Alexis Quinn

There are reasons why professionals should consider self-identification as valid and make reasonable adjustments to care and treatment (Hughes, 2020; Jones et al., 2024; Stubbe, 2024). The Equality Act (2010) applies to impairments, not diagnoses, so there is a legal right to reasonable adjustments when self-identifying.

- 1. Waiting times for diagnosis and cost.** Self-identification reflects a person's understanding of their own needs and might be necessary given significant waiting times for formal diagnoses – these can span years (Fisher et al., 2023; Fletcher-Wilson, 2024). Accepting self-identification allows for necessary support to be provided. Additionally, paying for private assessment is expensive and is often not accepted by the NHS.
- 2. Gendered diagnostic bias** is well-documented and means many women who are autistic can miss out on essential understanding and support because criteria are skewed towards male presentations (Fletcher-Wilson, 2024).
- 3. Focus on need rather than diagnosis,** acknowledges that everyone gets support based on their experiences rather than their label (Povey, 2015; Pritchard-Rowe and Gibson, 2024). Remember, that in the right environment, autistic people can flourish, meaning that they may not be considered to have sufficient difficulties for diagnosis.
- 4. Reduce anxiety and misunderstanding** by recognising that the perinatal period can be particularly stressful for autistic people who have unique sensory sensitivities, communication needs, and emotional responses – formal diagnosis or not. Implementing reasonable adjustments can significantly reduce anxiety and enhance care (Hampton et al., 2023).
- 5. Accepting self-identification can enhance support for maternal and infant wellbeing,** as lacking the right help can adversely affect both mother and baby.





Supporting sensory needs of autistic pregnant women and birthing people

Ninety-six per cent of autistic people will experience sensory processing difficulties. Pregnancy can bring about a range of different sensory experiences that may create stress and discomfort (Grant et al., 2025; Talcer et al., 2023). For instance, sensory sensitivities can be exacerbated by hormonal changes, physical discomfort, and environmental factors. Understanding what feels different and what to do about it is vital for promoting wellbeing during this transformative period.

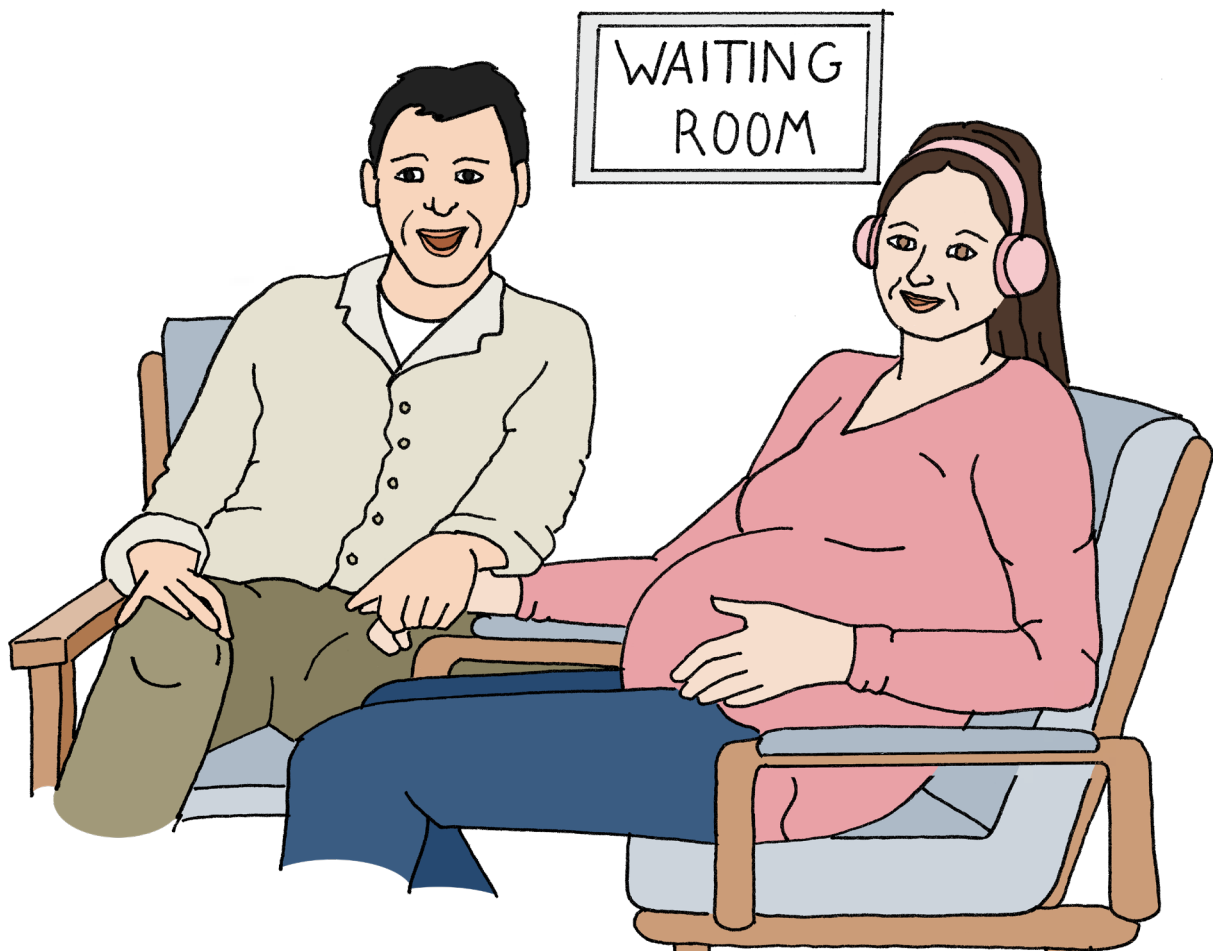
Sensory processing

Autistic people are likely to have varying sensory thresholds that may change during pregnancy and the post-partum period (Grant et al., 2025; Quinn, 2021); some people may seek out additional sensory experiences (and have or develop a higher than typical threshold), while others might become overwhelmed by even minimal stimuli (and have or develop a lower than typical threshold).

Increased reactivity to auditory, tactile and olfactory stimuli are very common, and can impact caregiving, social interactions, employment and organisation, leading to stress, fatigue and anxiety (Talcer et al., 2023). Sensory under-reactivity is less common and is known to result in reduced body awareness, e.g., clumsiness.

After birth, sensory demands, such as infant crying and noisy toys, can significantly affect wellbeing. Breastfeeding can be particularly painful and difficult due to tactile sensitivities (Grant et al., 2022), although it can also be a source of sensory regulation (Grant et al., 2023).

1. Understand that increased sensitivity can result in a need to withdraw from intense stimuli but can also make it difficult to do so as autistic people can struggle to think and act, e.g., they may become stuck.
2. An inability to withdraw can be perceived as threatening, increasing stress.
3. (Re)designing environments that consider sensory needs can be helpful, e.g., reducing lighting and noise can help reduce stress (see table below for some suggestions).
4. Downtime and creating calming spaces with low lighting, gentle sounds and soft furnishings, can reduce overwhelm.
5. (Online) communities for support, validation, and advice on managing sensory challenges can be helpful.



Considering sensory needs

Create a safe space for the person to discuss and express their sensitivities and freely use any existing strategies/things they have found helpful. Based on each sense, here are a range of recommendations to enhance wellbeing.

Sensory area	Low threshold suggestions	High threshold suggestions
Sight 	- Minimise bright lights. - Offer sunglasses or hats to reduce glare. - Relocate away from light source, e.g., window.	- Introduce (soft) lighting, e.g., seat person next to window. - Introduce light-based sensory tools, e.g., light-up fidgets.
Hearing 	- Limit loud noises. - Remove any beeping machines (where possible). - Consider ear defenders or noise-cancelling headphones. - Provide own room.	- Use background noise/music for comfort. - Engage in gentle conversation.
Touch 	- Reduce unnecessary physical contact. - Request permission before touch, e.g., a hug, applying gel/medical devices. - Use softer fabrics for bedding/clothing.	- Provide options for cuddly items, squeeze hugs, weighted blankets for support. - Wear tighter bra/clothes if possible.
Smell 	- Allow for open windows. - Create unscented environments. - Provide support for changing baby. - Reduce exposure to perfume, strong smelling foods, etc.	Use preferred scents like essential oils to create a calming atmosphere.
Taste 	- Address nausea if present. - Provide regular opportunities for snacks, drinks or gum (if helpful). - Consume less flavourful foods.	Allow flavourful snacks that are preferred or comforting as needed.
Balance (vestibular) 	- Offer advice on managing dizziness or discomfort during motion. - Create clutter free spaces. - Help organise areas where baby may be cared for.	Provide sensory breaks based on the person's preferred input, e.g., large medical ball to bounce/or swing, etc.
Body awareness (proprioception) 	- Provide fidget toys or stress balls to manage tension. - Orientate self to room/space. - Create clutter free spaces.	Encourage practices like prenatal yoga, swimming, etc., for physical awareness and grounding.
Interoception 	Regularly check in regarding basic needs (hunger, thirst, bathroom).	Adjust temperature comfort with layers or blankets as needed for personal comfort.

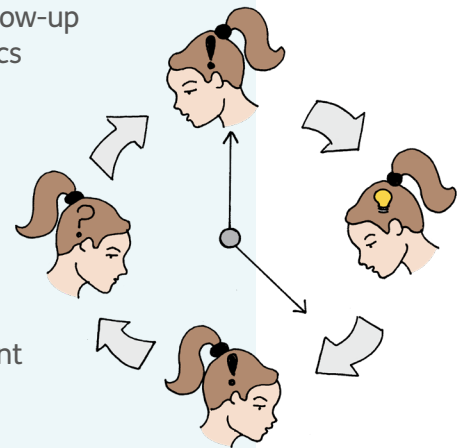
For breastfeeding sensory needs, see section on recognising and addressing sensory challenges, page 52.

Reasonable adjustments for autistic pregnant women and birthing people

To support the needs of autistic pregnant women and birthing people, read the following reasonable adjustments before meeting the person you are supporting. Then, using, [A practical resource for autistic pregnant women and birthing people: support, rights, and wellbeing](#), discuss what might be helpful with your client.

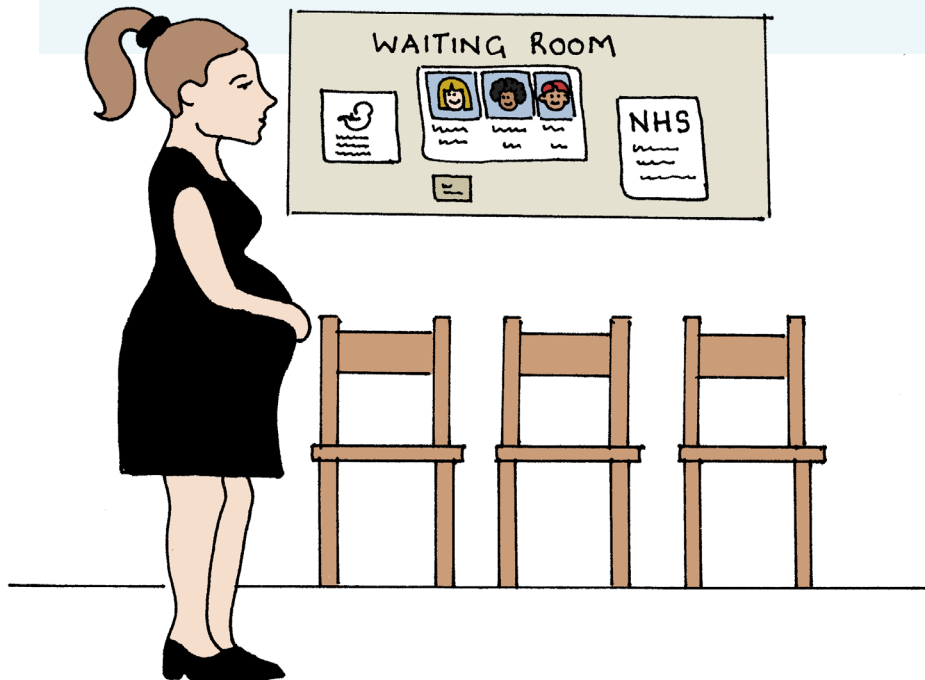
1. Time for processing

- **Extended appointments:** double appointment times to allow for review, questions and discussion.
- **Follow-up appointments:** offer additional follow-up sessions focusing on specific concerns or topics related to pregnancy/post-partum wellbeing.
- **Preparation materials:** provide written information ahead of time that outline what will be discussed during appointments and any tests that the person may wish to do.
- **Recap at the end:** Summarise key points and next steps at the end of each appointment to reinforce understanding. Have an option to email a summary (if helpful).
- **Buffer time:** schedule appointments at the beginning or end of clinic hours to avoid interruption from subsequent patients and/or be flexible with preferred morning/afternoon appointments.
- Accept that someone may ask questions you've already provided information about; there are many reasons for this, e.g., to increase predictability, check something out again, for reassurance or other reasons that you could be curious and kind about.



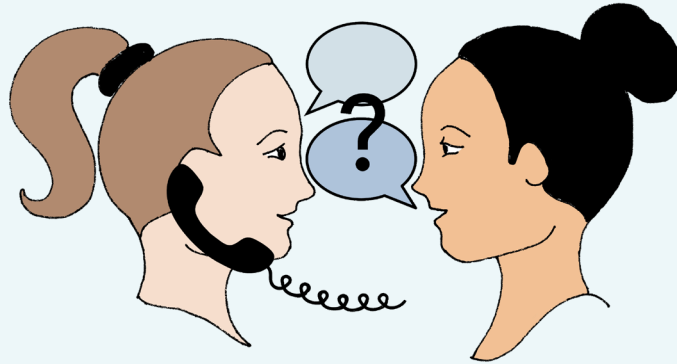
2. Reduce waiting time

- **Priority scheduling:** allows autistic individuals to book the first appointment of the day to avoid waiting.
- **Fast-track options:** coordinate with healthcare facilities to provide fast-tracking for essential services, like ultra-sound or emergency visits. If this is not possible, allow the person to wait in their car (if they have one) and be texted/called when the appointment is ready to attend.
- **Text or call notifications:** implement proactive communication methods to notify about any changes/delays before the scheduled appointment.
- **Waiting area adjustments:** provide an option to wait in a designated quiet area if available (or, as above in point 2, the person's car), minimising exposure to stress-inducing stimuli.
- **Home appointments:** explore the possibility of home and/or online consultations if these could be helpful.



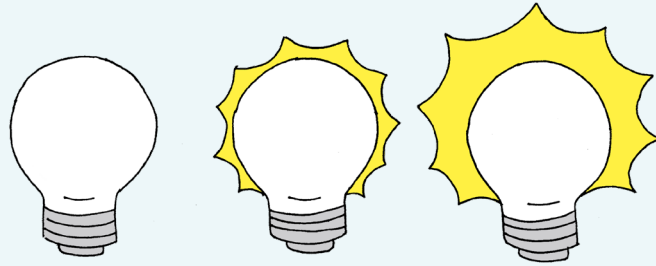
3. Communication-friendly strategies

(Also see section on enhancing mental wellbeing and providing emotional support, page 36).



- **Accessibility aids:** explore whether diagrams, charts, pictures or other physical aids, might help explain medical procedures or pregnancy stages. Refer people to autistic pregnancy books/information ([see page 6](#)).
- **Simplified language:** prepare information (or summarise what has been discussed in appointments) to explain medical terms or acronyms in plain English, avoiding jargon.
- **Accessible formats:** offer documents in various formats, such as large print, Braille, or electronic formats compatible with screen readers. Explore whether Easy Read would help, if the person has a co-occurring learning disability.
- **Personalised communication preferences:** document and respect individual communication preferences for recall, such as wanting a recording of the appointment, or textual summary post-appointment via email.
- **Recording appointments:** allow discussions to be recorded (with consent) so that information can be revisited at the person's own pace.

4. Environmental considerations



- **Quiet room:** ensure that there is a quiet room for waiting, minimising sensory overwhelm in busy medical facilities. Shared wards can be especially difficult; it can be helpful/necessary to offer a side room (if available) with the option to open/close curtains and clarify/enforce rules around visitor noise, etc.
- **Adjustable lighting:** provide options for adjustable lighting, allowing dimmed/natural lighting to cater to sensitivity.
- **Equipment:** turn off noisy equipment or use for a minimal time to cater for noise sensitivity. Explain the use of any other equipment and check for understanding and informed consent before proceeding.
- **Sensory-friendly decorations:** consider autism-friendly decor with soft colours and minimal patterns to create a calming atmosphere.
- **Temperature control:** allow for personal control of temperature, such as providing blankets or fans based on preference.

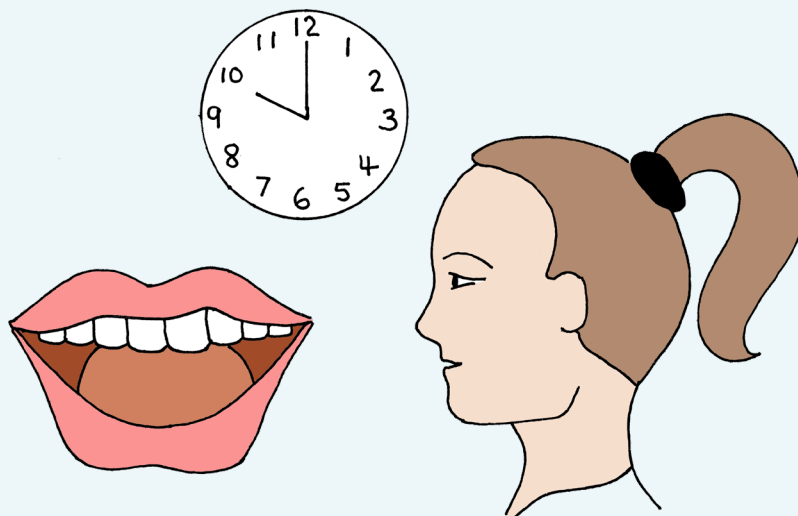
5. Support from familiar people

- **Designated care partners:** enquire whether the person's chosen family member(s) or close friend(s) want to attend appointments.
- **Inclusion in discussions:** enquire whether family or supportive others should be included in discussions about healthcare decisions and treatment options.
- **Open visiting hours:** allow caregivers or family members to remain with the individual during hospital stays or, when necessary, outside of regular visiting hours.
- **Agreement on support role:** develop a clear understanding of how the support person can help, whether it's through reminders or emotional support. It might be important for this to be documented if the plan is for the supporter to speak or make decisions on the person's behalf.
- **Coordination with care partners:** facilitate coordination with caregivers to ensure they are informed about medical histories, preferences and concerns.



6. Regular check-ins

- **Frequent appointments:** offer 2–4 week check-ins with a midwife/health visitor to review support and monitor physical and emotional wellbeing.
- **Symptom tracking:** help the person track/record symptoms, feelings and concerns, to discuss in appointments (if this is helpful for them).
- **Support group access:** signpost/facilitate access to support groups (which might be online) where pregnant (perhaps autistic) people can share experiences and coping strategies with peers. However, not all autistic people would find this helpful.
- **Wellness workshops:** organise workshops focusing on emotional wellbeing, coping mechanisms, and sensory processing strategies tailored for pregnant people.
- **Feedback:** provide opportunities to give feedback and ensure people are aware of feedback/complaint mechanisms .



10 tips for health care professionals in supporting autistic women and birthing people

Hayley Morgan

Childbirth can be an empowering, neuro-affirming life event, given the right support. Wherever you live in the UK, there are laws and guidelines available to help protect and provide guidance on your responsibility to help create an autism-friendly birth experience.

Here are 10 neurodivergent-affirming tips for healthcare professionals supporting autistic women and birthing people through childbirth:



1

Create a sensory-friendly environment: for autistic women and birthing people, sensory overwhelm can impact a person's right to communicate their pain levels or needs in birth. Minimise bright lights, loud noises, and strong smells in the birthing space. Offer noise-cancelling headphones or dim lighting options. Write collaborative birth plans and follow them – they may speak when the autistic person may find it difficult to.

People with lived experience say:

"It was more than wanting a posh spa experience in the delivery room, the noises and constant stream of people meant I felt my voice wasn't listened to. I was so overwhelmed I couldn't tell them about the pain I was in."

What research says:

Strömberg et al., (2022) suggest autistic participants reported greater discomfort with background sound levels in health care settings and felt more misunderstood by health care providers.

2

Provide clear and direct communication: use straightforward language and avoid medical jargon. Break down information into manageable steps to help redress inherent power imbalances. While autistic people can mask their true profile of needs, plain language and clear information will benefit all patients and professionals alike. This is crucial for shared decision making, as required for Code of Conduct adherence and patient safety.

People with lived experience say:

"I didn't know what the words meant, I felt like I agreed just to go along with it because I didn't want to admit that I couldn't understand what they'd just said."

What research says:

Como et al., (2019) suggest that unconscious biases towards autistic people in healthcare settings can be shown through unadjusted language use, impacting marginalisation and stigma, as well as being seen as a 'healthcare microaggression' to not consider accessible communication.

3

Offer predictability: share a detailed, realistic plan of what to expect during labour and delivery. Visual aids or written schedules can be helpful – chatting during antenatal appointments about communication preferences is key here.

People with lived experience say:

"I'd been told that I'd get a room to myself to give birth in. They hadn't said that I had to be pushing the baby out for that to be happen. The Ward was full of women with their babies, I thought I had to stay there."

What research says:

Hampton et al., (2022a, 2022b) suggests that pre-labour ward visits can help increase predictability and calm, as can hospital and staff familiarisation visits.

4

Respect sensory needs: be mindful of touch and physical contact. Always ask for consent before performing any procedures or examinations. This is essential for any patient, but particularly for autistic people who are more likely to have trouble communicating when overwhelmed, as well as more likely to have a history of sexual abuse, which can be triggered by unconsented touch. Also, remember that the sensations of pregnancy and birth have a whole host of interoceptive bodily changes that cannot be observed – not all sensory overwhelm is visible from the outside!

People with lived experience say:

"Childbirth was extremely triggering. I'd been SA'd as a kid and contractions felt the same kind of pain. I wasn't able to tell anyone about this but I think the stress made my contractions stop."

What research says:

Cazalis et al., (2022) states that 9 out of 10 autistic women have been victims of sexual violence. Trauma-informed care practices go hand-in-hand with caring for autistic women and birthing people. Continuing Professional Development (CPD) and autistic-led awareness courses can help improve knowledge of this.

5

Allow for individual preferences: tailor the birthing experience to the person's needs, such as allowing them to bring comfort items or people to support them. Autistic people's needs can be as different from each other as neurotypicals are from one another – they can also fluctuate from room-to-room or over a lifespan. Frequent check-ins are helpful once a strong rapport has been built with the person.

People with lived experience say:

"Having my fairy lights and fleece blanket with me added a touch of home. My husband also felt relaxed and he was better at telling them what I needed and about my birth plan when I couldn't talk."

What research says:

the Autistic Joyologist article (Butler, 2024) explains the autistic spiky profile concept well with recommendations, including focusing on positives and abilities. This is a great, interactive springboard to start from.

6

Be patient and flexible: understand that stress or sensory overload may affect communication. Allow extra time for decision making and responses. While certain protocols may not allow for this as easily, e.g., emergency surgery or intervention, coproduced but patient-led birth plans can help bridge the gap between protocol and practice, where neuro-affirming care can slip through the gaps.

People with lived experience say:

"I was trying to behave like a good patient. I kept quiet and agreed to what they said because I was in so much pain. It wasn't in my birth plan and wasn't what I wanted, but I didn't want them to think I was going against them. They already thought I was weird, so I didn't want to push it."

What research says:

Elliot et al., (2024) discuss inadequate perinatal care for neurodivergent people in terms of educating about, and accommodating for, multi-faceted needs in childbirth for autistic people.

7

Provide emotional support: validate their feelings and experiences. Avoid dismissing concerns as ‘over reactions’. One of the leading schools of thought in autism studies and advocacy circles, is the work of Damian Milton – his Double Empathy Problem theory states that autistic people are not a ‘broken’ version of neurotypical but rather see the world differently with a different set of values. Try seeing the world more neuro-affirmingly by educating yourself on autistic community voices and values in the perinatal period.

People with lived experience say:

“What was something not even worth noting for them meant a huge difference to me, it meant they saw me as less than, someone auditioning for my own child.”

What research says:

understand that the perinatal period can add new challenges that may otherwise have been manageable. Hampton et al., (2023) suggests that even routine self-care or errands can be over-whelming during pregnancy for some autistic people. Make sure the person’s needs are being met on a holistic basis, too.

8

Educate yourself: learn about autism and neurodiversity to better understand the unique needs of autistic individuals during childbirth. Autistic midwives and researchers head up an organisation called the Maternity and Autism Research Group (MARG) (www.maternityautismresearchgroup.co.uk). Campaigning and collaborating with institutions and individual health services to achieve change for perinatal care for autistic people, MARG hold events and signpost to research, resources and evidence-based tools. MARG co-founder and midwife, Diane Fox, created an e-learning course for midwives who want to learn more about autism.

People with lived experience say:

“My midwife on my second (child) took time out to educate herself a bit more (about autism). She read books in her own time to understand me and always wanted to listen and learn more. That made so much difference”.

What research says:

the Royal College of Midwives’ have resources, publications, events and webinars to provide support (<https://rcm.org.uk>).

Collaborate with the individual: involve them in decision making and respect their autonomy. Empower them to advocate for their preferences. This includes adhering to birth plans, accepting different forms of communication that you may not expect, giving processing time and more. While seemingly practical, these small fundamental steps to care can make all the difference to autistic people.

People with lived experience say:

"Knowing she (midwife) was listening to me and had read my birth plan meant I felt believed and cared for."

What research says:

Elliott et al., (2024) suggest that a compassionate, informed and autistic-led improved understanding of neurodivergence can lead to a more compassionate perinatal experience for autistic people.

Follow up postpartum: offer continued support after childbirth, recognising that the postpartum period can also present sensory and emotional challenges. Autistic women and birthing people may have more difficulty engaging and maintaining breastfeeding. However, some find breastfeeding to be a sensory cocoon that prevents overwhelm and promotes bonding. Getting to know the person's needs and changes are key.

People with lived experience say:

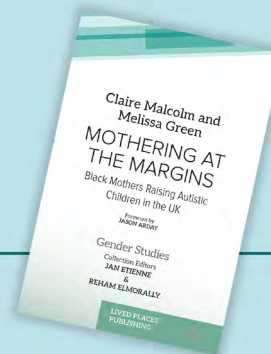
"The letdown reflex was painful and stressful. I didn't know what to expect and the health visitor just dismissed me when I asked about it."

What research says:

Dr Aimee Grant's (2024) 'Autistic pregnancy, birth and beyond: your questions answered' project has created an invaluable library of videos for autistic people and those supporting them. These are easily signposted to, are neuro-affirming, and full of helpful information.

Cultural inequalities and rights for all

Claire Malcolm and Mel Green



RACISM

65%

(almost two thirds) of black people (surveyed) said that they had experienced **prejudice from doctors and other staff** in healthcare settings.

This rose to three quarters

75%

among black people aged 18 to 34 (Kapadia et al., 2022).

Imagine what 'medical care' feels like from the perspective of someone whose identity sits at the intersection of racism, misogyny and ableism.

Now imagine the challenges that such a person faces in navigating services linked with pregnancy and childbirth.



60%

(nearly two thirds) of women (surveyed) in the UK said that their **health issues are not taken seriously.**

57%

(more than half) of women have had a **negative experience with a healthcare professional** (Azad and Barnes, 2024).

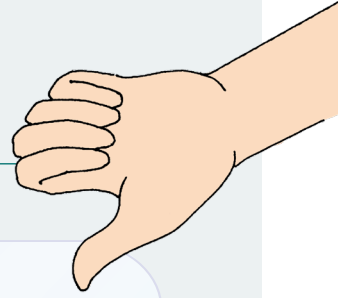
28%

(one in four) disabled people (surveyed) said that they had been **refused help when requesting support to understand information about their healthcare** (Healthwatch England, 2022).

MISOGYNY

ABLEISM

The impact of cultural inequalities



Medical racism:

- Baseless beliefs among medical professionals that Black people have 'thicker skin', 'harder veins', or a 'higher pain threshold'.

(Sabin, 2020)



Cultural incompetence:

- Racist assumptions concerning culture, lifestyle, and family life.



A deficit-based approach:

- Racially minoritised people dismissed as 'hard to reach' rather than as understandably suspicious of the medical profession.



Lack of empathy:

- Fear, anxiety, or frustration automatically misinterpreted as anger or aggression.



Silencing:

- Preferences and beliefs of racially minoritised and disabled people not sought, understood, or respected.
- Insufficient accommodations made for different ways of communicating.



Normalising suffering:

- Maternal mortality is twice as high among Asian women, and three times as high among Black women, compared with white women. This is all too often attributed to 'pre-existing conditions', or 'deprivation', as opposed to systemic racism.

(Felker et al., 2024).



How might professionals and supporters...?

- 👍 Confront your biases.
- 👍 Make space for race.
- 👍 Be neuro-affirming in your practice.
- 👍 Understand the difference between 'equality' and 'equity'.
- 👍 Listen differently.
- 👍 Be accessible.
- 👍 Prevent avoidable trauma.
- 👍 Hold yourself accountable.



Confront your biases:

- Reflect on the assumptions you make in your own practice, and the ways in which they relate to race, gender, and disability.



Actions:

For example, actively seek out anti-racism training and professional development.

Make space for race:

- Be mindful of the fact that racially minoritised people feel the impact of racism in all aspects of their lives. This can be traumatic. Be willing to do the work that may be needed to build trust.



Actions:

For example, create space for constructive discussions regarding how race might be an important consideration in pregnancy.





Be neuro-affirming in your practice:

- Remember that 'if you've met one autistic person, you've met one autistic person'. Take the time to learn about the individual needs and preferences of your patient and do all that you reasonably can to accommodate them.



Actions:

For example, encourage your patient to create a 'Pregnancy Support Plan', which can help you work with them to tailor a neuro-affirming birth plan.



Understand the difference between 'equality' and 'equity':

- Your instinct may be to 'treat all your patients in the same way', but this is ineffective and inequitable when some of your patients have more complex needs and circumstances than others.



Actions:

For example, where possible, plan for longer/additional appointments for neurodivergent patients, in line with a 'reasonable adjustments' approach.



Listen differently:

- Time is always at a premium in medical appointments, but it is vital not to 'rush' your patients, especially one whose racialised and neurodivergent identity ensures that they need and deserve thoughtful care.



Actions:

For example, do not be so keen to reassure your patient that you risk talking over them, or giving the impression that you are not taking them seriously.



Be accessible:

- Again, the amount of time you are able to spend with your patient won't always be in your control but do all you can to prioritise consistent access and support for those whose identities might otherwise result in marginalisation or mistreatment.



Actions:

For example, use whatever influence you can to ensure that patients with multiple marginalised identities have regular appointments with the same staff.



Prevent avoidable trauma:

- As much as you need to take every possible action to ensure a positive outcome, it is also crucial to prepare your patient for unforeseen circumstances. This is a particularly important consideration for those who might usually rely upon predictability and routine.



Actions:

For example, take the time to discuss contingencies and alternative interventions before they are needed, so that your patient feels as safe and prepared as possible.



Hold yourself accountable:

- The commitment to anti-racist, neuro-affirming healthcare is ongoing. Check in with yourself regularly to ensure that you are doing everything you can to put the 'patient' in 'patient care'.



Actions:

For example, keep a brief, anonymised, record of patient interactions that have led to opportunities for learning and self-reflection.

Enhancing mental wellbeing and providing emotional support on the pregnancy journey

Elena Sheldon, Alexis Quinn, Sara King and Vanessa Garrity

Why does perinatal mental health matter?

The perinatal period – pregnancy through to the first year after birth – is a time of major change. While this can be challenging for anyone, autistic women and birthing people may face unique and often overlooked challenges that can impact mental health.

Every autistic person has their own strengths, needs, and experiences. By listening and then making simple adjustments without judgment, professionals can make a significant difference.



Additional mental health challenges faced by autistic women and birthing people during pregnancy:

- Autistic women and birthing people often experience higher rates of postpartum depression and anxiety than non-autistic mothers.
- Mental health is impacted by heightened scrutiny from professionals, leading to fears of judgement or having parenting questioned (Lockington and Gullon-Scott, 2025; Quinn, 2021).
- Sensory sensitivities and a preference for routine might make adapting to the unpredictable nature of caring for a newborn more overwhelming (Westgate et al., 2024).
- Increased risk of perinatal distress can add to the emotional challenges faced during the postpartum period (Hampton et al., 2022a, 2022b).
- Autistic people often encounter societal judgement, which can lead to fears of being judged as a ‘good’ or ‘bad’ mother/parent, further impacting mental health (Quinn, 2021).
- Managing children’s needs within social settings, such as schools, can also be stressful, creating a cycle of worry and emotional strain for autistic parents (Rabba et al., 2024).

Improving care and communication with autistic people in the perinatal period isn’t just best practice – it’s essential to delivering accessible, person centred mental health care.



Supporting access to perinatal mental health services

Autistic people will likely face greater mental health challenges, but this is most likely due to external factors such as lack of support and understanding, rather than something inherently ‘wrong’ with the person. When services and the person’s wider community provide acceptance, tailored support and genuine understanding, many of these challenges can be greatly reduced or even eliminated.

Why do autistic people experience mental health challenges?

Systemic barriers and lack of support: many challenges stem from a lack of accessible, autism-informed mental health services and social support. When autistic people do not receive appropriate care, their experiences can be misunderstood/minimised, leading to feelings of vulnerability, frustration, isolation, and despair.

Social isolation and loneliness: autistic people experience and perceive the world differently. When services fail to accommodate these differences (especially during times of change), feelings of difference/isolation and a lack of meaningful support can worsen mental health.

Many autistic adults report their mental health affects their quality of life negatively, largely because of unmet needs and societal barriers (Mason et al., 2018). This is compounded by a lack of understanding and support (Adams and Young, 2021).

Autistic people learn to mask to fit in socially. This coping mechanism is born out of societal pressure to conform, leading to increased anxiety, depression, exhaustion and suicidality (Stimpson et al., 2021; Pearson and Rose, 2021), because it requires ongoing effort to hide authentic self.



Internal experiences and how maternity services impact autistic people



**Be sure to
be curious
and kind!**

Emotion recognition and communication:

some autistic people experience alexithymia, making it difficult to identify and express feelings. This is a natural variation in emotional processing, but services' misunderstanding often makes these experiences harder to navigate. When mental health issues aren't recognised or validated, seeking help and responding with compassion and understanding becomes more difficult; real mental health challenges can be confused, and services can react inappropriately – *be sure to be curious and kind!*

Persistent, repetitive thoughts: thought patterns, such as rumination, are natural autistic traits that can become more distressing without supportive interventions. When services dismiss these patterns, mistakenly view them as 'problems', or confuse them with other mental health challenges, it overlooks how external circumstances can exacerbate internal experiences and services can react inappropriately – *be sure to be curious and kind!*

Barriers to accessing support

Limited autism-informed healthcare:

Most autistic people find the mental health system unresponsive or unprepared to support their needs. Many encounter professionals who lack understanding of autism, which can lead to feelings of frustration and helplessness (Camm-Crosbie et al., 2019; Lipinski et al., 2022).

Misunderstanding and delay in getting an accurate diagnosis:

This delay can intensify feelings of confusion and frustration, further damaging mental wellbeing (Beck et al., 2020; Castañeda, 2023; Zener, 2019).

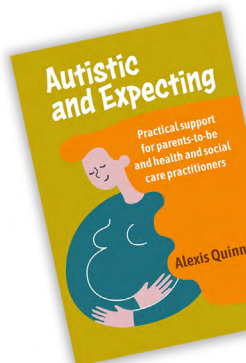
Consequences of unmet needs:

When appropriate, tailored support is unavailable – whether due to systemic gaps or societal misunderstanding/attitudes – autistic people's distress can escalate, causing services' responses to feel less supportive and helpful.

Supporting autistic people within perinatal mental health services

Getting through the door isn't enough. Autistic pregnant women and birthing people need to feel seen, safe, and supported.

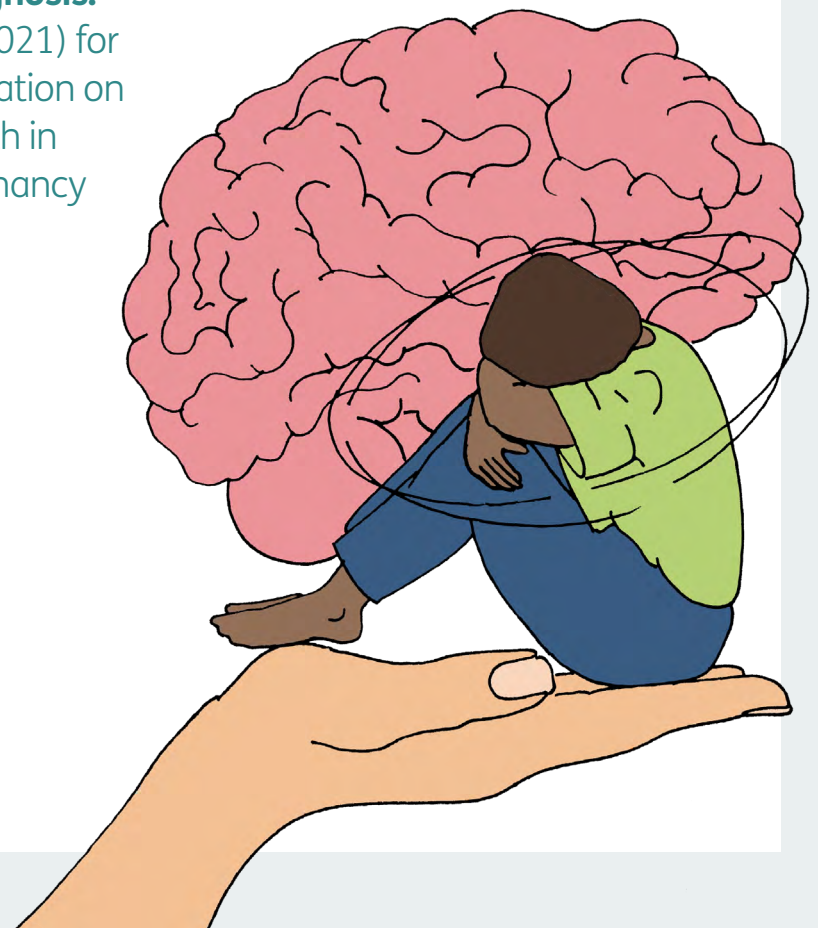
Use *Experience Sensitive Support* (McGreevy et al., 2024) within the SPELL Framework (Beadle-Brown and Mills, 2018) to help provide bespoke support.



Person centred care is key

Good care focuses on the individual's needs – not just diagnosis.

See Quinn (2021) for more information on mental health in autistic pregnancy and beyond.





Structure –

create a predictable environment that fosters comfort:

- Allocate and maintain consistent staff.
- Schedule appointments according to the person's preferences (see section on reasonable adjustments, page 19).
- Offer space tours (video or in-person) during quiet times.
- Teach supportive coping strategies, such as breath work, grounding techniques, etc., and suggest these are built into the person's schedule.



Positivity –

provide warm, non-judgemental support that celebrates individuality:

- Use open, friendly communication that helps the person feel heard and respected.
- Actively validate feelings, experiences, and choices – this is the person's journey, and their voice is valid.
- Respect uniqueness, avoid labels, and focus on strengths and preferences.



Personal journey –

support hopes, plans, and transitions with care:

- Help articulate goals and dreams for pregnancy, birth, and beyond.
- Support the person to prepare for upcoming changes or transitions, ensuring the person feels in control.
- Minimise disruptions by providing clear, consistent communication that might link what has happened with what is happening now and next steps, e.g., changes in support so that the person knows where they are in space and time.
- Validate each phase of the journey.



Empathy and insiderness –

to build trust by understanding perspectives:

- Listen with compassion and curiosity, giving space for feelings and stories (without interruption or judgement).
- Accept difficult feelings, such as distress, anxiety, or grief – they deserve recognition and support. Do not blame the person for distressed reactions – be curious about needs being unmet.
- Honour personal narrative as (the person's) truth, and empower their sense of agency and input.
- Tailor support strategies, respecting individual experiences and identities.



Low arousal –

for sensory comfort and agency in decision making:

- Minimise environmental stress and offer sensory tools to create calming spaces (see section on supporting sensory needs, page 16).
- Help/teach the person to create/schedule sensory and communication breaks and how to reconnect with their calm.
- Be flexible and ready to revisit plans, championing choices.



Links –

for togetherness, meaningful connections and coordinated support:

- Maintain open communication across healthcare teams to ensure seamless care.
- Involve trusted loved ones, e.g., partners, family, friends, in planning and support roles.
- Promote social networks, such as community groups or support circles to strengthen their sense of belonging.
- Build a nurturing, trusting relationship that prioritises safety and emotional wellbeing.



Sense making –

to help understand and find meaning in experiences:

- Encourage conversations about feelings, hopes, and fears.
- Support creative expression, such as journaling, drawing, or other arts to explore emotions and thoughts.
- Provide useful resources to help normalise feelings and clarify uncertainties.
- Ask reflective questions to help process the pregnancy journey, birth, and changing identity.

Potential risks if needs are not met

The majority of autistic pregnant women and birthing people accessing perinatal care will thrive with the right support. However, where a person's needs are not met, distress can occur. These may include overload, meltdown, shut down, trauma reactions, such as flight/fright/freeze/fawn and autistic burnout, as well as other mental health conditions (e.g., anxiety and depression). Poor services can also result in non-attendance, autistic elopement (a flight response to overwhelm), and consent being assumed rather than implicitly given. Quotes from autistic women participants from a recent PhD research project (King, 2025) describe some of these experiences first hand:

Autistic elopement

"I was put on a ward with 6 other women, and it was late at night, and there was talking and noise and I found it very stressful, and I guess I tried to ... I don't know, run away, leave ... or waddle away because I was quite heavily pregnant. And a midwife found me in a corridor with my husband, who was trying to calm me down, and he had to explain, because I was non-verbal, that I was autistic."

Another woman shared a similar experience of escaping the overwhelm of the postnatal ward:

"I really wanted out. I was not dealing well with it at all. But I also didn't feel ... I felt so overwhelmed, I felt so overwhelmed with everything else, having to learn how to breastfeed, to change nappies. Everything was so new that it was almost like again, you know the buffer. I didn't get to say, this is awful for me. Can I just go home, please? I'll sign anything. If I die on the way home, it's my fault, but I cannot be here. But I didn't have this ... the, I don't know, the RAM (processing capacity) again to get to the point where I felt like I could say, 'I can't be here. This is awful.'"

A different woman described her experience of hiding in the toilets because of overwhelm:

"So, in my birth preferences document, I said I wanted the lighting low, I wanted noise and disruptions to be kept to a minimum. I wanted questions to be put to my partner first rather than me. Erm, I mean, I had an eye mask on in labour, cause I didn't wanna see people. I just wanted to be left alone. I just kept hiding in the toilet. I just wanted to be on my own. Let them try and get me out the toilet. And I found it really stressful."

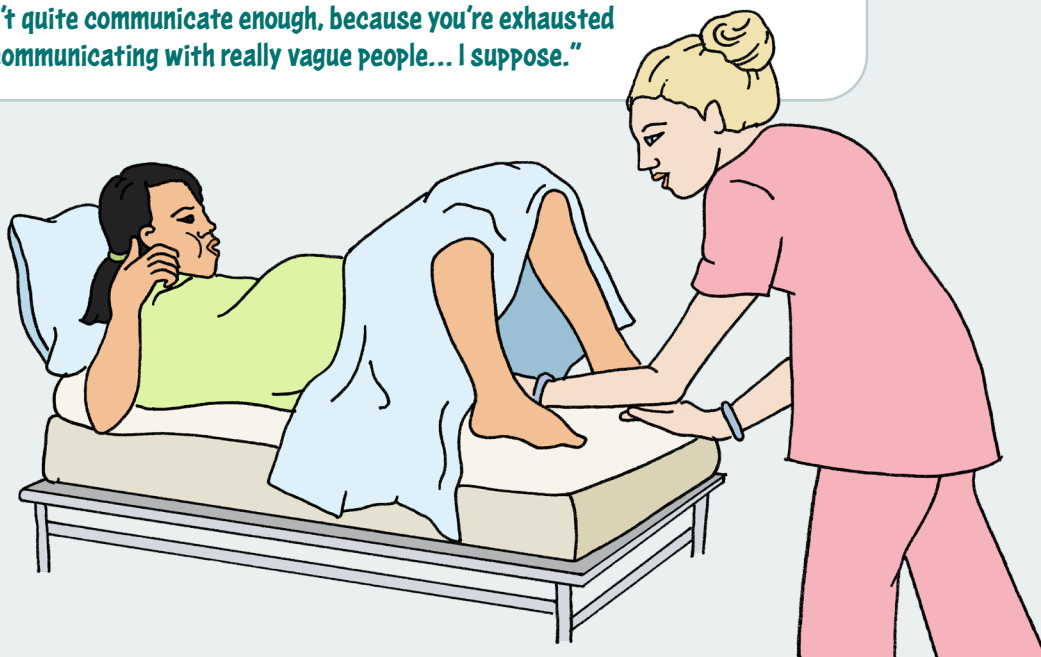
Communication

A different woman described her experiences of trying to navigate the telephone triage system when she thought she was in labour, evidencing the potential risk of her not being able to access the telephone system to attend hospital in labour:

"And I found the same as well, this really ambiguous 'call us when you're having 4 sets of contractions in 10 min'. And it's like that's really ambiguous. And every time I call you with what I believe is what you set these goalposts and you're telling me that I'm not ready. And then that sort of inhibited pre-labour more. And I was like actually finding these calls ... really stressful and then so I sort of gave up. I just went well, bugger it like. I just ... I can't be bothered with the hospital and it was kind of as I let go of that erm ... tension around communicating. But these people who just seem to be moving the parameters of you know, labour. That's when my waters broke, and that was kind of like, quite ecstatic, like, yeah, you need to go to hospital now."

When prompted further about what would have happened if her waters hadn't broken, she went on to say that she felt she may have been at risk, as she wouldn't have been able to go into hospital without being able to navigate the telephone system:

"This is a risk with me. It's shutting down on my communication to the point where I don't communicate at all and then going ... because I gaslight myself with my own interpretation of what's going on in my body. It's just like, well, apparently, I'm not even in labour, so oh, hello, baby, you've just suddenly appeared. Yeah, so the risk is disengagement and having a baby without any support or getting into a situation where it becomes too distressing, and then you're, you should have gone in earlier or something serious being missed, because you can't quite communicate enough, because you're exhausted about communicating with really vague people... I suppose."

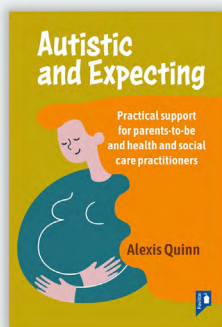


Consent

The quote below describes a participant experience where she felt she had not had sufficient processing time to consent:

"I didn't have time to process it. I just kind of agreed and I don't know why, I agreed. I think because in my mind I'd kind of made peace with the fact that if things didn't go to plan that I could... I'd looked up about gentle caesareans and at that point that if I could have an elective gentle caesarean that I could just about ... do that if, if it was necessary. But I think she jumped on that and booked me in, which was not quite what I was saying."

With appropriate sensory and communication adjustments, these experiences of overwhelm may have been avoided, ensuring that these autistic women could access care in a way that met their needs, reduced risks, provided more confidence about informed consent, and maintained their wellbeing.



Please see Quinn (2021) for more information about autistic mental health and how to provide mental health support effectively.

Supporting autistic women and birthing people with lactation

Ella Jackson and Alexis Quinn

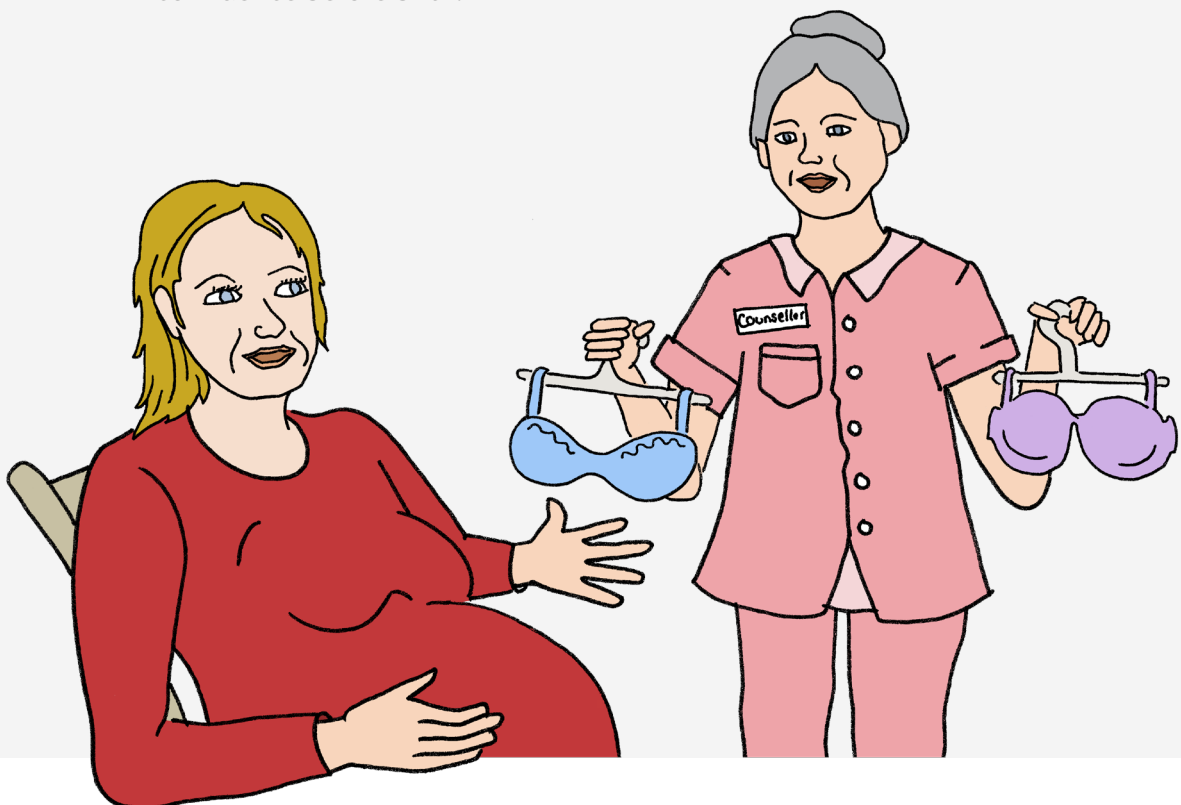
Supporting autistic women and birthing people with breastfeeding requires understanding, patience, and tailored approaches that respect their sensory, communication and emotional needs.

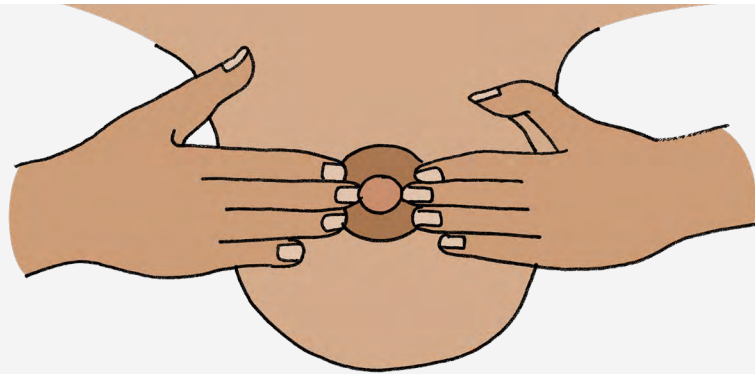


Antenatal preparation: foundations for success

Preparation before birth is crucial. Autistic pregnant women and birthing people often come with extensive knowledge and research about breastfeeding, however this knowledge can be difficult to apply and transfer. As such, it can be helpful to tailor support, recognising their expertise and the ways that you can accommodate sensory and communication preferences in practice (Grant et al., 2022).

- 👍 **Use strengths and routines:** identify what already works for the person, whether that's visual aids, written instructions, or specific sensory tools. Incorporate these into planning (Grant et al., 2022).
- 👍 **Provide specialised support and connect with the person's support early:** ideally, connect families to autistic care providers with additional lactation knowledge. Early, consistent support creates trust and enables personalised strategies (Grant et al., 2023).
- 👍 **Facilitate early referral:** around 28 weeks, schedule video or face-to-face meetings with the infant feeding maternity team. This early engagement allows comprehensive planning, introduces support services, and builds confidence before birth.





Discuss physical and sensory changes

Understanding physical changes helps prepare the person for what to expect:

Lactogenesis I (from 16 weeks): explain that the breasts will start preparing for milk production, e.g., they may feel heavier or tender. Enquire about whether extra sensory support would be helpful, e.g., wearing supportive bras with thicker straps (e.g., late in the pregnancy) could manage discomfort.

Areola and nipple changes: explain darkening and size may increase and is normal. Make sure the person knows nipples may become sensitive. Use visual aids, diagrams or body mapping tools during consultations. It's important not to ask for body exposure – always maintain privacy and consent.

Nipple sensitivity: autistic people may have higher – or lower sensory threshold ([see section on supporting sensory needs, page 16](#)). Practising techniques like reverse pressure softening can help soften the tissue and prepare for latch. Supporting partners to learn this technique may help. People might also like to trial breast pads in advance so that they can find ones that feel tolerable (Grant et al., 2023).

The role of scent and bonding

Explain that the scent of Montgomery tubercles can play a key role in bonding. The scent signals safety and familiarity, and trigger early feeding reflexes. NOTE: some autistic people may have heightened olfactory sensitivities; supporting gentle skin-to-skin contact offers comfort and fosters bonding without overwhelming the senses.

Managing post-birth sensations and pain

After birth, many mothers and birthing people can experience cramping or pain (afterpains). For neurodivergent people, unrecognised pain or a full bladder can intensify discomfort.

You might recommend:

- 👍 **Planned reminders** for bladder emptying, e.g., use alarms or support from partners to prevent unnecessary overwhelm/distress.
- 👍 **Offer pain relief before feeds** to ease cramping and discomfort.
- 👍 **Avoid full bladder or bowel** in the first days to help reduce pain and support relaxation and effective feeding.

Postpartum support for establishing milk flow

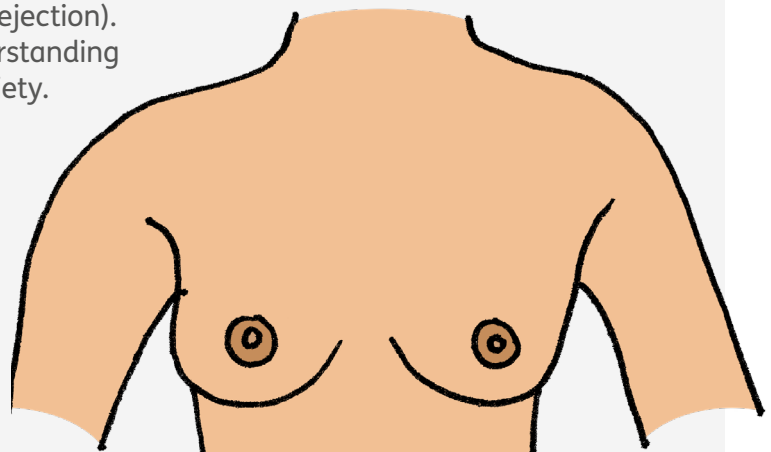
Breastfeeding success depends on creating the right environment and understanding each person's sensory and emotional state.

Engorgement and sensitive support

Engorgement after assisted births or C-sections may cause significant discomfort. Use reverse pressure softening to soften the breast tissue gently, reducing pain and enabling latching.

Support partners: if both are comfortable, partners can assist with these techniques. Sometimes, simple interventions like gentle massage or moving to a usual sitting position can help alleviate tensions and it may be more comfortable for the person feeding.

Let-down reflex: some people experience tingling or hormonal shifts (dysphoric milk ejection). Validating these feelings and understanding they are hormonal can reduce anxiety. Support can include pre-emptive hand expressing or using calming or distracting sensory tools during feeds.



The first hours and natural reflexes

New parents need to know that the first hours after birth are vital for establishing feeding. During this time, supporting your client to follow their baby's natural instincts can significantly enhance bonding and milk production. You might help the parent:

-  **Create a calm, sensory-friendly environment:** dim lights, soft sounds, and familiar sensory comforts help reduce overstimulation.
-  **Prioritise skin-to-skin contact:** immediate skin-to-skin contact can regulate blood sugar, temperature, and heart rate, while triggering the baby's natural feeding reflexes. However, not all autistic people will want to do skin-to-skin and this is ok. It can be shared
-  **Respect the baby's patterns:** observe their movements – bobbing, stretching, turning – and show them how to respond gently. This is their way of preparing to feed and these should not be rushed or forced.
-  **Support the instinctual phases:** the baby needs uninterrupted time to process and follow their reflexes. Make sure the parents know that lifting or forcing the baby to the breast before these stages are complete can cause distress (for parent and baby) and disrupt hormonal stimulation.

Supporting the hormonal cascade

The hormonal processes of oxytocin and prolactin are essential for successful breastfeeding. When the environment is stress-free and the baby is allowed to move through these reflexes, these hormones are naturally released, supporting milk flow. Babies often sniff as a way of getting to know the parent.

-  **Encourage partner involvement:** studies show that if the partner holds the baby in skin-to-skin contact for at least an hour, it supports early brain wiring for nurturing (Johnson and Slauson-Blevins, 2022).
-  **Allow early bonding:** allow all family members to spend time with the newborn, which helps everyone feel connected and supported.
-  **Personalise the feeding space:** create a calm, familiar, grounding area that fosters comfort and relaxation for the parent (Talcer et al., 2023).



Supporting days 1–3: building confidence and normalising variability

The initial days are a time of adjustment. Recognising normal behaviours and sensory responses helps prevent distress.

Day 1: recovery and bonding

- Autistic parents may benefit from knowing that the first hour could focus on family bonding and watching the first movements, not necessarily feeding.
- If fluids or medications were given during labour, let the person know their breasts may feel engorged and/or be less responsive. Suggest that gentle reverse pressure softening and reassurance can help.

Days 2-3: establishing feeding patterns

- Support the person to be patient with cluster feeding. Reassure it is normal and helps establish supply.
- Support positions that reduce sensory overload; side-lying (e.g., including away from overwhelming input, such as light sources) and/or laid-back feeding can be comfortable options.
- Continue skin-to-skin contact and observe cues for hunger or readiness.
- Monitor hydration and comfort, e.g., ensure the parent has support to meet their self-care needs.



Second night and beyond

- Night times can be challenging due to sleep deprivation and increased unpredictability with feeding demands.
- Support in adopting side-lying or low-light routines can ease this period.
- Reminder that engorgement, leakages, or increased milk volume are normal and temporary.
- Help establish feeding and self-care routines.

Day 5: when concerns arise

- If the baby has lost more weight than expected, discuss options, such as supplementation. Ensure the parent feels supported and confident, knowing that they can work towards getting back to exclusively breastfeeding by pumping between feeds, if this is something they want to do.
- Recognise that sleep deprivation impacts executive functioning and encourage resting during the baby's naps or when support is available.
- Make sure they have enough sensory support to modulate if/when overwhelm occurs.
- Support with expressing or using sensory tools can help manage sleep and overwhelm/stress.



Recognising and addressing sensory challenges

Different sensory thresholds can influence the feeding experience. Support involves validating sensory experiences and offering flexible solutions. Consider:

- **Using sensory aids**, e.g., textured pillows, calming scents, or noise-cancelling headphones, etc.
- **Modified clothing**, e.g., zips sewn into favourite clothing for easy access can make feeding more manageable.
- **Flexible positioning**, e.g., experiment with reclined, side-lying, or supported positions to aid comfort.
- **Visual aids**, e.g., diagrams showing attachment or latch technique improve understanding without verbal overload.
- **Monitor and adjust**, e.g., always check for signs of distress or discomfort and adapt support accordingly.
- **Offer different environments**, e.g., provide low-arousal spaces or quiet corner zones (during feeding) and ensure the parent can take sensory breaks (before and after feeding or at other convenient times during the day).



Managing pain or discomfort

- Many autistic people experience pain differently. Check this out with them.
- Most nipple pain can be addressed through correct attachment and positioning.
- For hypersensitivity, nipple shields (used with support) can reduce discomfort and aid latch.
- Reverse pressure softening, e.g., a gentle finger technique to soften tissue before latch.
- Apply a cold compress to assist in reducing swelling or discomfort.
- Help support partners to assist with techniques, reducing stress during early days. This can especially help if there is tactile defensiveness as the person may feel more comfortable with their partner helping.
- If using pumps, check for properly fitted nipple shields and pumps, offering support in selecting the right size and assisting with proper use.

Effective communication and support strategies

See section on reasonable adjustments ([page 19](#)) and section on supporting autistic people within perinatal mental health services ([page 36](#)), for communication support and also consider:

- Using visual aids and written materials, e.g., models of the breast, diagrams, step-by-step guides, and visual cues, help clarify techniques and support understanding without verbal overload.
- Respecting boundaries and privacy, e.g., avoid unnecessary body exposure, and always seek explicit consent to look, touch or have discussions about physical changes.

5 key reminders for professionals supporting autistic breastfeeding

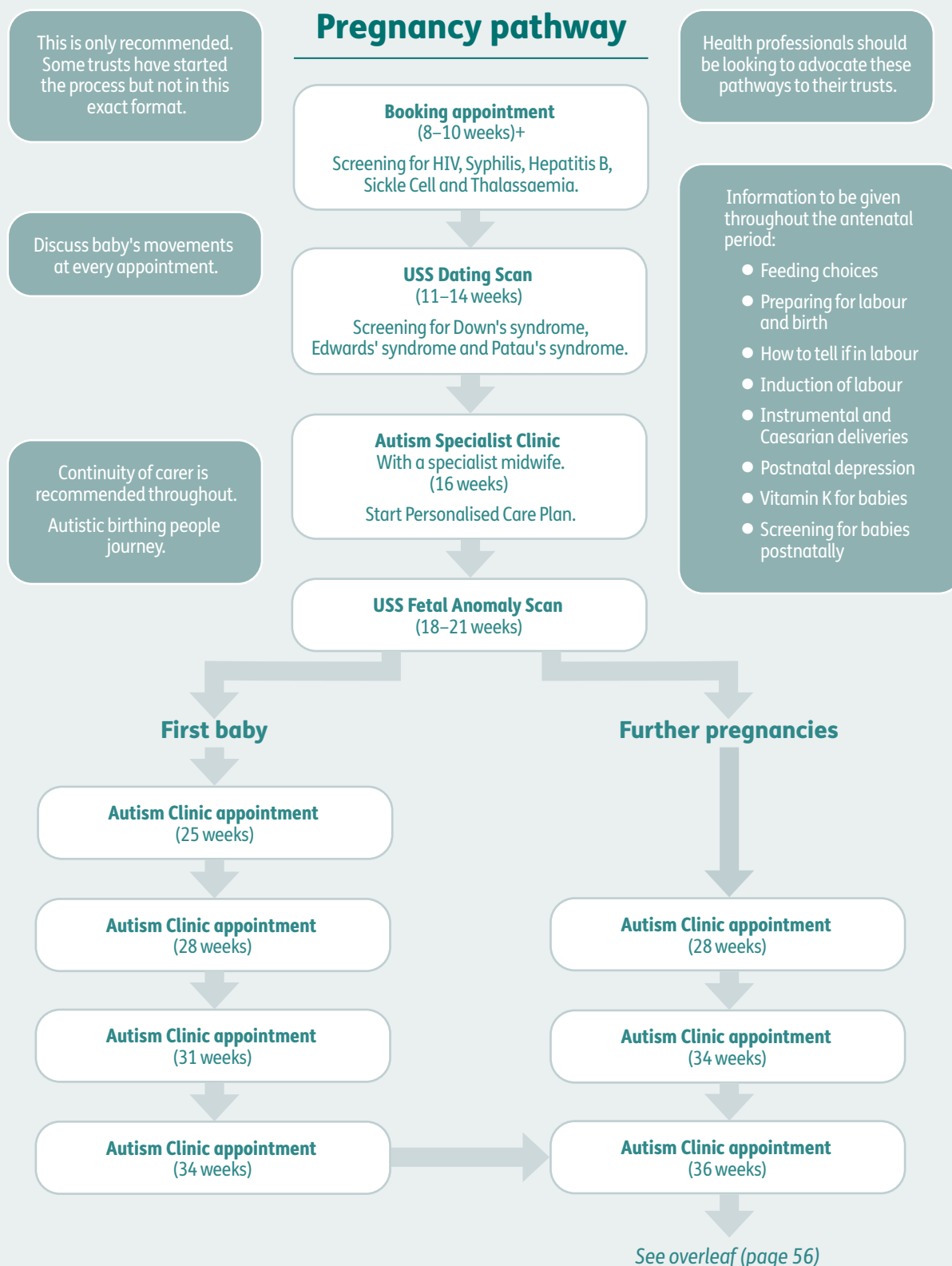
Supporting autistic women and birthing people in breastfeeding isn't just about technical support; it's about creating an affirming, flexible, and sensory-aware environment. It's about feeding in their way.

Remember:

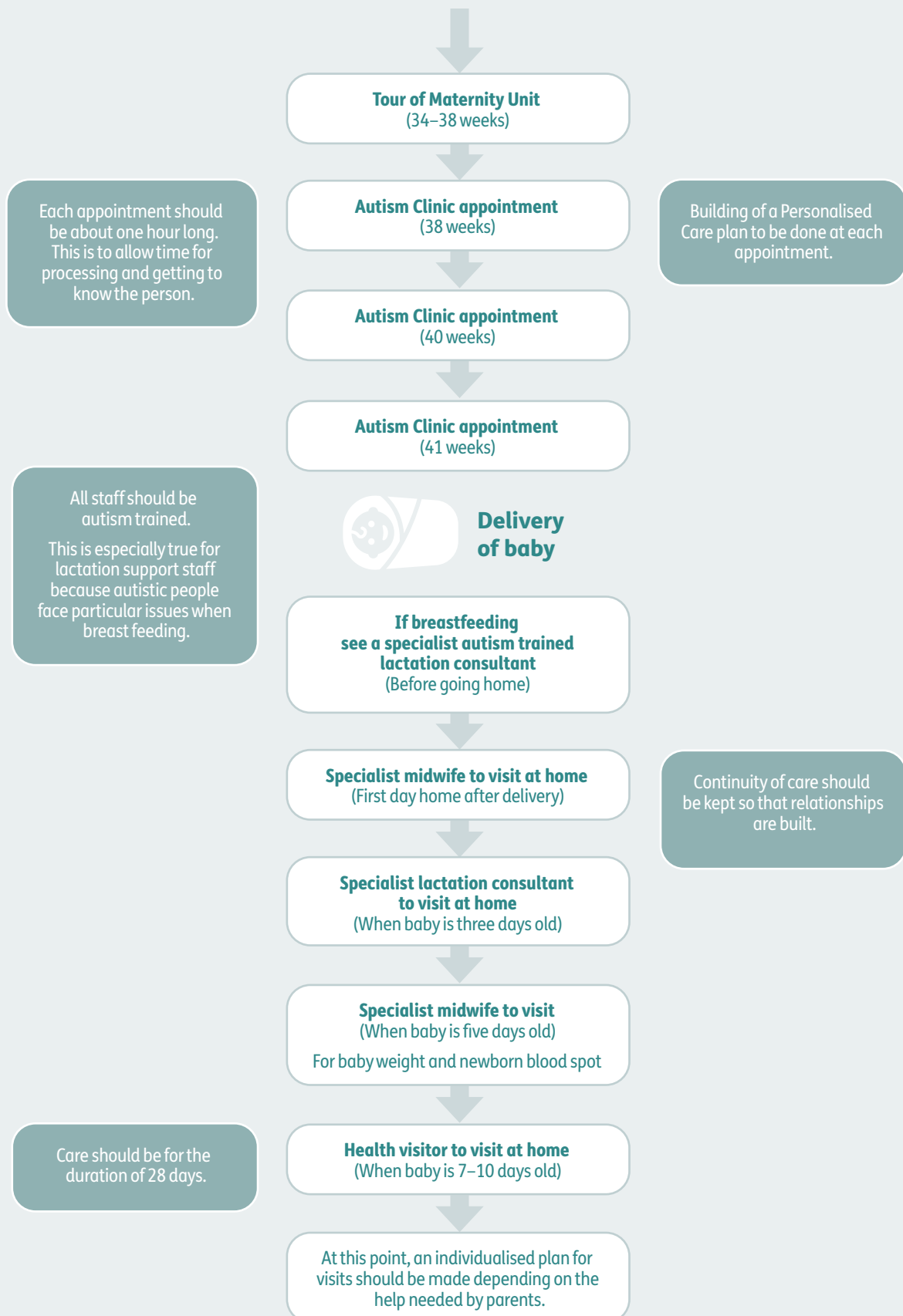
-  **Plan ahead:** early antenatal discussions and preparations increase predictability and familiarity.
-  **Validate sensory experiences and (re)assess regularly:** avoid assumptions about pain or discomfort and offer options that support sensory comfort. Monitor for signs of ineffective feeding or distress and adapt plans accordingly.
-  **Respect individual preferences:** find positions, routines, and communication styles that work for each person. Always explain the 'why' behind recommendations, supporting informed decision making.
-  **Encourage patience and trust:** natural reflexes are powerful and disruption can cause unnecessary distress.
-  **Collaborate with specialists:** ensure support is person centred, evidence-based, and that everyone understands the neurological and sensory needs of your client.

Suggested pregnancy pathway for autistic people

Stacey-George Hemes



Continued from page 55



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