Healthcare
Provider
Resource

Disability and Pregnancy: Accessible Pregnancy Care Planning Toolkit

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Sunnybrook
HEALTH SCIENCES CENTRE

Provincial Council for Maternal and Child Health
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Contents

About This Toolkit

This toolkit has been developed to support healthcare professionals in addressing the unique challenges faced by pregnant individuals with physical disabilities. It includes a Comprehensive Pregnancy Care Checklist and a Complex Case Conference Template, in an effort to bridge the existing clinical care gap. The toolkit aims to enhance the quality of care, reduce barriers to access, and promote inclusivity for pregnant individuals with a physical disability. Recognizing that rural, remote, and community care providers may lack access to some of the resources noted in this document, the toolkit is designed as a guide for providers to consider the unique care requirements of this population. It strives to enable care providers to deliver optimal patient-centered care and high-quality services, even in settings where resources may be limited.

Intended Audience

This toolkit has been designed for primary care providers, obstetricians, midwives, nurses, occupational therapists, physical therapists, social workers, physiatrists, neurologists, pain medicine specialists, anaesthetists, lactation consultants, dietitians, and other professionals involved in prenatal care, labour and delivery, and postpartum care.

Background: The Need for this Toolkit

Many people with physical disabilities can have healthy pregnancies; however, there is an increased risk of adverse outcomes for pregnant individuals and neonates, including preterm birth, preeclampsia, and caesarean birth[1]. Antenatal care often requires interdisciplinary consultation and planning to manage both obstetric concerns and the impact of pregnancy on that individual's underlying condition, which could include autonomic dysreflexia, increased spasticity, respiratory complications, venous thromboembolism, renal dysfunction and bladder management complications[2,3]. There are significant barriers to accessing prenatal care for people with physical disabilities, including transportation complexities, lack of accessible care spaces and difficulties finding physicians comfortable providing obstetrical care to this population[4]. This increase in clinical complexity and difficulties accessing care has created a significant clinical care gap. Additionally, this population group has historically been excluded from opportunities to provide input into efforts regarding their wellbeing[4].

The Accessible Pregnancy Care Planning Toolkit serves to address the intricate clinical care requirements of this demographic. It bridges the existing care gap by embodying a person-centred approach for comprehensive and individualized care during the course of pregnancy and beyond. It includes two tools for healthcare providers: the Comprehensive Pregnancy Care Checklist, a foundational framework for creating personalized care plans, and a Complex Case Conference Template, aiding in structured interdisciplinary case conferences for complex medical cases, promoting effective communication and coordinated care.

Measures to Enhance Care for Pregnant Individuals with Physical Disabilities in a Healthcare Setting

People with physical disabilities experience pregnancy at approximately the same rate as people without physical disabilities; however, they can encounter significant barriers when trying to access care. Some individuals with physical disabilities face increased pregnancy risks and complex care needs, requiring an interdisciplinary approach. The following measures should be considered to enhance care for pregnant individuals with physical disabilities:

- **Person-Centred Care:** Birth care should be provided in a person-centred manner, which may include involving partners in positioning for caesarean births, organizing photographs of the birth when general anaesthesia is needed, and supporting breastfeeding postpartum, including those receiving care in the intensive care unit.
- **Staff Training:** Staff members may undergo specialized training in mobility device operations.
- **Electronic Medical Record (EMR):** EMR could include tabs related to disability in pregnancy.
- **Accessible Space:** Ideally, the healthcare setting should be equipped with wheelchair-accessible facilities, including a scale, washrooms, and an ultrasound room with a ceiling-mounted lift.
- **Birthing Suite:** Ideally, the birthing suite would feature a wheel-in shower for accessibility and adequate space for safe operation of mobility equipment.
- **Consolidated Care:** Care should be consolidated when possible, enabling pregnant individuals to see multiple specialists and allied health providers in one location.
- **Pre-Visit Preparation:** Contacting referred individuals in advance of an appointment could help in preparing for the initial visit, taking into account equipment and transportation needs.
- **Interdisciplinary Collaboration:** Specialists in physical disability and pregnancy should collaborate to provide comprehensive care.
- **Lactation Support:** Individuals with physical disabilities wishing to breastfeed may benefit from receiving support from a lactation consultant before birth.
- **Community Resources:** Ideally, community resources should be identified and discussed early in the care process.
- **Case Conferences:** Case conferences held before delivery, involving all relevant teams and specialties, along with the pregnant individual and their support person, to address equipment, planned and emergency situations, and postpartum concerns may be beneficial for some individuals.

Source of Information

The information in this document is adapted from The Accessible Care Pregnancy Clinic – DAN Women and Babies Program at Sunnybrook Health Sciences Centre. The Comprehensive Pregnancy Care Checklist was developed by the clinic in a person-centred manner with input from people with physical disabilities, community leaders, and an interdisciplinary team including maternal-fetal medicine, anaesthesia, haematology, neurology, physiatry, respirology, endocrinology, advanced practice nurses, team leaders, lactation consultants, dietitians, and social workers. The Complex Case Conference Template was developed to guide interdisciplinary case conferences for those with medical complexity.

Using the Comprehensive Pregnancy Care Checklist

This checklist can be used as a guide when considering potential aspects of care needed for individuals with physical disabilities during pregnancy. Due to the diversity of concerns that may arise for people with physical disabilities during pregnancy, not all aspects of this checklist will apply to every patient's care or care centre. Individualized care should be directed by the primary care provider.

Comprehensive Pregnancy Care Checklist

This checklist should be completed through the continuum of care where timelines are guided by gestational age in weeks.

1. Initial phone conversation[1,2]

- ☐ Introduction to the clinic
- ☐ Review medical history
- ☐ Review any physical/mobility limitations
- ☐ Review equipment that may be needed for the appointment
- ☐ Review need for attendant to be arranged for the appointment
- ☐ Review appointment details and check-in process
- ☐ Discuss potential need to book extra time for bloodwork PRN
- ☐ Review accessible parking
- ☐ Review patient transportation to appointment and discuss directions to the clinic, if applicable
- ☐ Review scheduled drop-off and pick-up times if using publicly funded transportation
- ☐ Email communication to clinic team of new patient and equipment that may be needed for the appointment

Notes
1. This is intended to take place prior to the first appointment.
2. The purpose of the call is to plan for the first appointment to ensure that it flows smoothly.

2. Prior to 12 weeks, or at First or Second Meeting

- ☐ Review and document health history
- ☐ Describe program and available supports[3]
- ☐ Discuss options of early anatomy scan (13 – 16 weeks), and/or genetic testing, if indicated
- ☐ Consider screening for diabetes – Hemoglobin A1C with routine antenatal bloodwork or with
- ☐ FTS and/or NIPT
- ☐ Consider routine screening for urinary tract infections
- ☐ Discuss COVID, flu and other vaccines as applicable
- ☐ Weigh wheelchair, if applicable, and document[4]
- ☐ Obtain height and document[5]
- ☐ Discuss ultrasound timing and equipment needs[6]
- ☐ Discuss prenatal bloodwork, FTS or consider NIPT PRN[7]
- ☐ Discuss frequency of visits
- ☐ Discuss transportation needs
- ☐ Discuss going to hospital with any acute changes to status, or concerns <20 weeks GA
- ☐ Discuss and anticipate the changes to one's adaptive devices as the pregnancy progresses
- ☐ Review available resources within the organization and in the community
- ☐ Open the discussion for making adaptations at home in preparing to bring the baby home
- ☐ Screen for intimate partner violence during pregnancy[8]
- ☐ Discuss option to communicate with primary RN to coordinate care via email and sign email
- ☐ consent form PRN
- ☐ Review of function[9]

Notes

3. Publicly funded resources for preparing for parenthood may take many months to set up; therefore, it is important to start talking about it early.
4. Often a suitable time to weigh the wheelchair is while the person is having their NT ultrasound done.
5. Height may need to be estimated from ulna length or knee height.
6. Consider early referral to assess mobility equipment needs. Consider OT home assessment to facilitate safe home environment and anticipate physical changes with pregnancy.
7. Pregnant people may or may not wish any genetic testing/early anatomy screening, especially for conditions that they themselves have. Introduce this topic in an open and respectful manner.
8. Pregnant people with physical disabilities may be at risk of violence or abuse. Clinicians should be attuned to this and be prepared to discuss again as needed throughout the pregnancy.
9. Review of function will be different for each person, but could include changes in mobility, balance, pain, neurological symptoms, spasticity, bowel and bladder functions, breathing, falls, skin changes, and/or autonomic dysreflexia.

3. 12 Weeks – 16 Weeks

- ☐ Discuss frequency of visits
- ☐ Discuss ultrasounds and opportunity to have same technologist scan, when possible
- ☐ Consider early anatomy scan, PRN
- ☐ Consider baseline pulmonary function testing for those with known decreased lung capacity or if
- ☐ symptomatic[10]
- ☐ Consider thromboprophylaxis[11]
- ☐ Consider cervical length assessment[12]
- ☐ Review of function[9]

Notes

10. Pregnant people with a history of decreased lung capacity or with reported shortness of breath should have early pulmonary function testing.
11. Pregnant people who use wheelchairs most of the time or have limited lower body mobility should be referred to haematology for consideration of thromboprophylaxis.
12. Pregnant people with spinal cord injuries (including Spina Bifida) have a higher rate of preterm delivery and may benefit from cervical length assessment starting at 16 weeks on a case-by-case basis.

4. 16 Weeks – 20 Weeks

- ☐ Discuss anatomy scan and opportunity for longer booking to accommodate positioning and need for breaks[13,14]
- ☐ Open discussion regarding GCT
- ☐ Screen for intimate partner violence during pregnancy
- ☐ Review of function[9]

Notes

13. Some pregnant people will need extra time or breaks during the anatomy scan.
14. If the Hoyer lift is required, consider location, timing, and communication with US team.

5. Week 20 – Week 24

- ☐ Consider pulmonary function testing PRN for those with risk factors[15]
- ☐ Discuss fetal movement monitoring
- ☐ Consult anaesthesia to address options for pain management in labour, as well as in the postpartum period[16]
- ☐ Discuss coming to hospital with any acute changes to status or concerns
- ☐ Discuss detection of contractions for those who cannot feel contractions[17]
- ☐ Discuss GCT
- ☐ Open discussion of plan for mode of delivery
- ☐ Open discussion for need for baby care after delivery, family physician or paediatrician
- ☐ Review of function[9]

Notes

15. Baseline pulmonary function testing should be done around 28 weeks for pregnant people with identified risk factors such as scoliosis or use a wheelchair most of the time; therefore, the consult should be placed at this time.
16. Anaesthesia consult should be done around 28 weeks; therefore, arrange the consult during this period of time.
17. Pregnant people with a spinal cord lesion above T10 may not perceive uterine contractions.

6. Week 24 – Week 28

- ☐ Discuss frequency of visits
- ☐ Follow up on referrals to date
- ☐ Tdap and RhIG PRN
- ☐ Continue to discuss mode of delivery with insight from anaesthesia/respirology consults
- ☐ Discuss prenatal class options[18]
- ☐ Discuss finding newborn care provider
- ☐ Discuss timing of delivery PRN
- ☐ Screen for intimate partner violence during pregnancy
- ☐ Public Health program for antenatal and postpartum support referral PRN[19]
- ☐ Discuss available community supports
- ☐ Review of function[9]

Notes

18. Examples of prenatal class options include those in group settings, one-on-one sessions with a prenatal educator, or online options if offered by the organization.
19. Consider Public Health programs for antenatal, postpartum, and breastfeeding support.

7. Week 28 – Week 32

- ☐ Discuss plan for case conference and invite patient and support persons PRN[20]
- ☐ Open discussion regarding feeding plan and consider need for lactation consultant
- ☐ Follow-up discussion for need for baby care after delivery, family physician or paediatrician
- ☐ Public health program for antenatal and postpartum support referral PRN[21]
- ☐ Review of function[9]

Notes

20. If a case conference is planned, the person and their support person should be invited to participate to ensure person-centred care.
21. Not all pregnant people will require a formal case conference. Those that are less complex may need a written summary emailed to the birthing unit.

8. Week 32 – Week 36

- ☐ Case conference[22]
- ☐ Review plan and supports on day of delivery
- ☐ Update the care plan as per case conference and document accordingly
- ☐ Discuss and arrange tour of birthing unit PRN
- ☐ Discuss delivery events/process PRN
- ☐ Screen for intimate partner violence during pregnancy
- ☐ Review of function[9]

Notes

22. Finalized copy of the case conference summary to be posted on EMR and patient chart. Hard copy of the care plan will be kept in the clinic patient binder in Triage.

9. Week 37 – Delivery

- ☐ Give a hard copy of the case conference summary to the patient[23]
- ☐ Ensure hard copy of plan is in the chart in birthing unit

Notes

23. Initialized hard copy of the case conference summary will be provided for the pregnant person to bring with them when they go into labour or if the need arises to visit triage ahead of scheduled induction of labour or C/S.

10. Postpartum

- ☐ Remote phone follow-up at one-to-two weeks postpartum or PRN until six-week visit
- ☐ Screen for intimate partner violence in postpartum
- ☐ Public Health postpartum support referral PRN[24]
- ☐ Discuss mental health/coping
- ☐ Remind person about breastfeeding resources PRN[25]
- ☐ Review of function[9]

Notes

24. If referring to a Public Health program, normalize that this resource is for all new parents.
25. Breastfeeding considerations for parents with a spinal cord injury includes breastfeeding can cause autonomic dysreflexia.

11. Final Six-Week Visit

- ☐ Discuss mental health/coping
- ☐ Screen for intimate partner violence
- ☐ Discuss supports – refer to supports PRN
- ☐ Discuss and provide community resources PRN[26]

Notes

26. Community resources include:
    a. Public Health brochure
    b. Nipissing Developmental Screen
    c. Vaccination Schedule

Consultation Checklist

Discipline		
☐ **Anaesthesia**	Date/Time:	Practitioner:
☐ **Haematology**	Date/Time:	Practitioner:
☐ **Respirology**	Date/Time:	Practitioner:
☐ **Neurology**	Date/Time:	Practitioner:
☐ **Cardiology**	Date/Time:	Practitioner:
☐ **Urology**	Date/Time:	Practitioner:
☐ **Pain Clinic**	Date/Time:	Practitioner:
☐ **Genetics**	Date/Time:	Practitioner:
☐ **Seating Clinic**	Date/Time:	Practitioner:
☐ **OT/PT**	Date/Time:	Practitioner:
☐ **Registered Dietician**	Date/Time:	Practitioner:
☐ **Social work**	Date/Time:	Practitioner:
☐ **Psychiatry**	Date/Time:	Practitioner:
☐ **Breastfeeding Clinic**	Date/Time:	Practitioner:
☐ **Other**	Date/Time:	Practitioner:

Additional Test Checklist

Tests		
☐ **NT Scan**	Completion Date:	Results:
☐ **eFTS**	Completion Date:	Results:
☐ **NIPT**	Completion Date:	Results:
☐ **Early Anatomy Scan**	Completion Date:	Results:
☐ **Amnio/CVS**	Completion Date:	Results:
☐ **EKG/Echo**	Completion Date:	Results:
☐ **PFT**	Completion Date:	Results:
☐ **Early GCT**	Completion Date:	Results:
☐ **Other**	Completion Date:	Results:

Community Resource Checklist

Organization		
☐ **Publicly funded resources e.g. Nurturing attendant**	Date:	Comments:
☐ **Transportation needs**	Date:	Comments:
☐ **Public Health resources e.g., HBHC**	Date:	Comments:
☐ **Hospital/Community pregnancy and parenting resources e.g., CILT**	Date:	Comments:
☐ **Accessible baby equipment resources**	Date:	Comments:
☐ **Perinatal Classes**	Date:	Comments:
☐ **Birthing Unit tour**	Date:	Comments:
☐ **Other**	Date:	Comments:

Patient Addressograph

Complex Case Conference Template

Complex Case Summary and Management Plan

Blood type:

Serology: Rubella: Hep B SA, HIV, VDRL:

Diagnosis and Patient Profile:

1. Primary diagnosis:
2. Past medical and surgical history:
3. Mobility:
4. Mobility devices:
5. Obstetrical risks:
6. Risk of Autonomic Dysreflexia:
7. Mode of delivery and other special considerations:

Obstetrical History:

Medical/Surgical History:

Allergies:

Current Medications:

Summary of Consults

Anaesthesia

Practitioner: Date of Consult:

a) Key points of discussion:

b) Plan for delivery and postpartum:

Haematology

Practitioner: Date of Consult:

a) Key points of discussion:

b) Plan for delivery and postpartum:

Respirology

Practitioner: Date of Consult:

a) Key points of discussion:

b) Plan for delivery and postpartum:

General Surgery

Practitioner: Date of Consult:

a) Key points of discussion:

b) Plan for delivery and postpartum:

Breastfeeding Clinic

Practitioner: Date of Consult:

a) Feeding Plans:

b) Plan in postpartum:

Delivery Plan: Mode of Delivery (MOD), Location, Date and Time

Mode of delivery

Location of delivery:

Planned date and time (if scheduled) of delivery:

Special equipment:

Special notes*:

- ☐ Case conference summary in EMR
- ☐ Case conference summary – Hard copy in clinic patient binder in Triage
- ☐ Care conference summary to patient – Hard copy + e-copy
- ☐ Consider pre-op admission PRN
- ☐ Special notes for planned delivery – i.e., consider photos PRN
- ☐ Private room for mobility accommodations
- ☐ Autonomic dysreflexia risk assessment

Plan for Emergency Delivery

Confirm location of OR (Notify consultants PRN)

- ☐ Birthing Unit
- ☐ Main OR

Special notes*:

* Special notes: e.g., consider notifying other consults who should be in the delivery, special equipment for delivery

Plan for Spontaneous Labour (No Emergency)

- ☐ Counsel patient on indications to present to Triage or nearest ED
- ☐ Discuss delivery and postpartum plans with the patient; invite and encourage active participation in case conference
- ☐ Give patient the case conference summary – Hard copy + e-copy
- ☐ Case conference summary uploaded to EMR and charting systems; hardcopy in clinic patient binder

Special notes*:

Postpartum Plans

- Consider private room to accommodate mobility and medical needs PRN
- Additional anaesthesia request in postpartum – Consider risk for autonomic dysreflexia and post op monitoring. May include need for longer arterial line monitoring and PP epidural (BP and HR, pain management)
- Consider DVT prophylaxis in postpartum
- Breastfeeding – Consider risk for potential trigger of autonomic dysreflexia with breastfeeding for some patients
- Consider urinary care (e.g., foley catheter may need to stay in longer)
- Consider postpartum pain management
- Some may need longer hospital stay

Specific postpartum needs:

* Special notes: e.g., consider notifying other consults who should be in the delivery, special equipment for delivery _

References

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Appendix A: Feedback on the Care Checklist from People Living with Physical Disabilities Who Had Given Birth

Re. Assistive Technologies

"...it's something that should be discussed early on so at least they can start thinking about what they would need and whether it's things that they can adapt, buy store-bought items, or that sort of thing."

"Maybe in the first trimester…Even if they are buying baby clothes, buy something which is easy for them to put on. Things like that."

Re. Anesthesia/pain management

"I think even with either natural delivery or a C-section, you're sitting up in a chair, it's not really getting a chance to heal and, you know, it's quite tender and sore down there, and a lot of women tend to have pain for several months post-delivery. So, talking about pain management strategies… I think is something that needs to be discussed."

Re. Communication/ Continuity of care

"If you can develop some kind of a protocol, what kind of things to be done during delivery, I think that will help in remote areas where there is not much of this care available."

"One thing that came up a lot in my research was the lack of continuity of care, the disconnect between hospital and community services. I think we need to look at bridging and partnering with our community partners, so individuals don't feel like they're falling through the cracks."

Re. Breastfeeding

"I think there should be a lot of emphasis also near the tail end of breastfeeding assistance, because breastfeeding is quite a challenge."

Re. Violence

"It's really, really important or significant, I think, to ask women about experiences of violence."

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