Pregnancy Considerations for Women with Disabilities

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Conflicts of interest

- None

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Magee Womens Hospital – Center for Women with Disabilities

The Center for Women with Disabilities at Magee-Womens Hospital of UPMC has been delivering state-of-the-art preventive health care to women with disabilities since 2001.

One of the first such services in the country, the center was designed in consultation with women with disabilities to meet their needs for accessible, regular exams and screenings.

Learn more about our facility »

We offer a comprehensive, patient-centered model of care that encourages and facilitates equal access and accommodation of physical differences.

Services We Provide

Contact Us
Center for Women with Disabilities
306 Hotlot St.
Suite 5000
Pittsburgh, PA 15213
Phone: 412-641-4030

Hours of Operation:
Friday - 9 a.m. to 4:30 p.m.

Complete a contact form »

Referrals
When it is necessary to refer our patients to other physicians, we refer them to physicians who also have accessible equipment.
Why does reproductive healthcare present unique challenges to women with disabilities?
Synergistic challenges in reproductive healthcare for women with disabilities

- Women with disabilities may face the greatest barriers in the healthcare system when trying to receive reproductive healthcare.
Synergistic challenges in reproductive healthcare for women with disabilities

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  - Strong medical and community culture surrounding pregnancy and birth has a concerned with idealistic views of “health” and absolute focus on avoiding birth “defects”
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  - Strong medical and community culture surrounding pregnancy and birth has a concerned on perfect health and birth defects
  - Obstetricians are risk-adverse, are very concerned about issues that they can’t control, worried about medico-legal issues
What are common types of disabilities among reproductive-aged women?
Types of disabilities

- Mobility
- Intellectual
- Sensory
Characteristics of disabilities

- Congenital or acquired
- Physical or mental
- Continuous or episodic
- Visible or hidden
- Static or resolving
- Mild or severe
Common types of disability-related conditions among reproductive-aged women

- Spinal Cord Injuries
- Multiple Sclerosis
- Cerebral Palsy
- Intellectual Impairment
- Visual Impairment
- Hearing Impairment
- Spina Bifida
Basic Office Skills for Reproductive Health Visits
Healthcare providers lack skills relating to disability care

- 81% of medical students have no clinical training in disability care
- 75% of medical residencies have no clinical experience in disability care
- 58% of medical school deans reported that a curriculum for disability care was not a high priority
- 44% of Ob/Gyn clinics reported being unable to provide for people with mobility disabilities (highest among any surveyed specialty)

Basic office skills

- The main challenge is getting to know the specific needs and past experiences relating to each woman with a disability.
- Each person is different as well as their capabilities relating to being able to perform the routine tasks of an office visit (including history taking and physical examination).

What limits access to quality community health care for women and girls with disabilities?

- Office space (doorway width, ramps): 53.3%
- Height of exam tables: 58.3%
- Accessible radiology equipment: 56.7%
- Stigma about women with intellectual disabilities: 70%
Preparation for a visit

- Helpful to know specific, intensive needs of each patient with disabilities beforehand
  - Flag visits with helpful information including need for extra staff members, special equipment, etc.
- Increase the length of the scheduled appointment
- Learn where resources like patient lifts or transfer boards are located
Preparation for a visit

- May be helpful to patient or custodial facility to group appointments (including radiologic testing on the same day)
- Practicing performing pelvic exams with special, unfamiliar equipment may be helpful
- Use the largest available room with an electric lift exam table
- Have two staff in room to help patient and provider
Useful equipment for an OB/GYN exam
Performing a complete OB/GYN history

Special focus on

- Reproductive history and plans
- Sexual activity and dysfunction
- Expectations and concerns about pregnancy
- Past pelvic exams history and experience
- Affects of pelvic discomfort on spasticity, history of autonomic dysreflexia

Performing a OB/GYN exam

- Offer help with transferring to exam table
- Offer help with stability on exam table
- Do not perform exams in wheelchair (i.e. breast exam) unless there are no other options or preferred by patient
- Use of larger leg supports (or manual assistance holding legs) are generally more helpful than normal stirrups
Performing a OB/GYN exam

- When positioning, watch for
  - Impaired balance
  - Spasticity
  - Skin pressure, especially over sacrum
  - Contractures (the use of gentle movements is best, some patient need muscle relaxants like baclofen)
  - Anxiety (some patients will be medicated with a benzodiazepine for transport)

Performing a Ob/GYN exam

- When a pelvic exam is indicated:
  - Communicate about actions clearly and ask for feedback
  - Gentle exam (can help prevent spasticity)
  - Consider topical lidocaine
  - Consider emptying the bladder
  - Finding a position that work best for the patient’s body
  - Use instruments to provide maximum comfort

Considerations for pregnancy
Pregnancy

- Many barriers to care for women with disabilities
- Women report that clinicians lack insight into their interest in pregnancy and childbirth, lack knowledge about pregnancy-related needs, and fail to consider the patient’s knowledge and experience about their own disabilities
- Clinicians report lack of any training and report previous negative experiences, but describe care as very rewarding when the patients expectations are met and clinicians feel comfortable with the process

Considerations for preconception counseling
Preconception counseling

- There is social pressure not to conceive
- There is less shared knowledge about the experience of pregnancy and particular disabilities (on patient’s or provider’s side)
  - More shared knowledge available through internet communities
- Consideration of effects of disability on pregnancy
- Consideration of effects of pregnancy on disability
Preconception counseling

- Finding a provider willing to care for pregnant women with disabilities is often reported to be very difficult.
- Establishing a great provider-patient relationship is vital to allow for open, honest communication.
- Preconception OB visit recommended for people with disabilities.
- Preconception consultations with rehabilitation doctor (for patients with SCI) or neurologist (for MS) or urologist (for women with adapted urinary systems) are helpful.
Preconception counseling

- Consider current medications, possible fetal effects, and alternatives (especially anti-epileptics, anti-psychotics, etc.)
- Consider whether other medical conditions will likely improve or worsen during pregnancy
- Consider how to differentiate between pregnancy-related symptoms and disability-related symptoms
- Discuss personalized genetic counseling
Genetic counseling

- Genetic counselors has often had a complex relationship with disability rights advocates
  - Genetic counselors often have little experience living with the conditions they discuss and generally focus on most negative aspects or extreme cases

- Women with disabilities often have considered, more than most women, the idea of having a child with a disability

- Do not make assumptions about patient attitudes toward screening or genetic conditions

- Consider risk related to congenital disability

- Discuss normal genetic screening


Considerations for antenatal care
Antenatal issues

- Each person is different, even if they have a similar condition or injury
- Increased frequency of UTIs, constipation, muscle spasticity, seizure activity, and fatigue
- Change in body mass and center gravity, and concern for causing fetal trauma lead to increased concern of falling, leading to decreased activity and/or increased use of assistive devices, altered fix of prostheses or adaptive equipment
- Increased risk of pressure injuries, fatigue, musculoskeletal pain
Spinal Cord Injury

- No affect of fertility
- In first trimester, common issues may be with autonomic dysreflexia (next slide), urinary tract infections, and constipation
- In second trimester, common issues may be increasing difficulty with mobility, bladder health, skin care, and muscle spasms
- In third trimester, common issues may be breathing discomfort, blood flow issues, and fatigue
Autonomic Dysreflexia (ADR)

- A loss of coordinated autonomic response to a noxious stimuli below the level of spinal cord injury leading to diffuse vasoconstriction and hypertension
- Only occurs when SCI is at the level of T6 or higher
- Possible outcomes of severe cases include hypertensive crisis causing intracranial hemorrhage or seizures and bradycardia causing cardiac arrest
- As pelvic exams, pregnancy, or vaginal delivery can both trigger ADR
- Chronic and acute cases can be effectively managed with knowledgeable providers
Spina Bifida

- No effect on fertility for women
- In pregnancy, expect frequent UTIs, possible ventriculoperitoneal shunt issues
- For patients with ventriculoperitoneal shunt, vaginal delivery is much preferred to cesarean delivery
- Universal latex allergy
Multiple Sclerosis

- No effect on fertility
- Pregnancy is associated with decrease in disease-related symptoms
- Pregnancy does not change the long-term course of MS
- Altered sensation may make labor difficult to anticipate and labor may bring on increased spasticity
- Weakened motor muscle strength increases likelihood of operative delivery

Cerebral Palsy

- Fertility is not affected by cerebral palsy
- Issues with difficulty with mobility, increased pain, spasticity in pregnancy
- Need for individualize positioning during labor and delivery due to contractures
Hearing impairment

- Your face is an essential communication tool, speak directly to patient (not to interpreter)
- Speak normally, but in short, simple sentences
- Be prepared to write down questions or answers, provide written instructions
- Establishing effective communication for questions and concerns in important throughout pregnancy to decrease the risk of complications

Intellectual disability

- Mild intellectual disabilities can be difficult to identify
- Insuring that each woman has the proper support available through family and community social supports
- Screen for abuse
- Allow for more time to communicate and answer questions

Considerations for labor and childbirth
Labor issues

- Women with disabilities may benefit strongly to touring childbirth area to understand the capabilities of the facility and help anticipate challenges and areas needing adaptation.
- Antepartum consultation with obstetric anesthesiology will help with pain control planning
- Discussion of birth plan
- Cesarean delivery is sometimes indicated, but vaginal delivery is a healthy option for many women
Preparing for labor

- Assistance and planning concerning monitoring for symptoms of preterm labor, preterm premature rupture of membranes, etc.
  - Partners and caregivers can learn to palpate for uterine contractions
  - Women with SCI may note increase muscle spasticity during early labor which may help them recognize early labor
  - Childbirth and breastfeeding classes can be very helpful
  - Uterine activity monitors are available
Spinal Cord Injury

- Many of the normal symptoms of labor may be present, but some may be absent
- In labor, it is difficult to differentiate between pre-eclampsia and autonomic dysreflexia.
  - Watch for BP changes related to contractions, bradycardia, and lack of proteinuria, flushing, goosebumps, and diaphoresis
Multiple Sclerosis

- Decreased muscle strength may make second stage of labor (pushing) more difficult
  - Operative vaginal delivery may be necessary

Considerations for postpartum care
Postpartum issues

- Challenges related to parenting of newborn is often overwhelming to providers, but many excellent adaptive tools and equipment are available.
- Longer postpartum admissions may be helpful for education/observation.
- Patient support organizations for particular conditions can be very helpful.
- Education and identification of postpartum depression is always important!
Postpartum issues

- Routine examination of perineum, careful use of products such as ice packs for people with decreased sensation, lactation support for people with low sensation near breasts
- Rehabilitation occupational therapists can work with postpartum nurses to problem solve with child care issues
Resources
Resources

• There are excellent advocacy groups for type of disability, and they all have sections (with pamphlets and videos) on healthcare interactions

• To name a few: United Spinal Association, Spina Bifida Association, United Cerebral Palsy, National Down Syndrome Society, The Arc (intellectual and developmental disabilities), American Foundation for the Blind, National Association of the Deaf

• For providers, ACOG has an excellent Women with Disabilities website including a 552 slide PowerPoint with audio recording!
Resources

- scisexualhealth.ca

Female Fertility and Pregnancy

Overview

This section includes information and resources for planning and preparing for pregnancy, and how to manage pregnancy and childbirth with an SCI.
- What Is It?
- What’s Different Now?
- What Can I Do About It?
- What Do I Need to Know?
- Who Can Help Me?
- Conclusion & Resources
Resources

• [www.nationalmssociety.org/](https://www.nationalmssociety.org/)
Resources

- [http://www.capability-scotland.org](http://www.capability-scotland.org)

**Pregnancy and Parenthood for People with Cerebral Palsy**

**Thinking of having a baby?**
This fact sheet has been put together with mothers and fathers with cerebral palsy (CP) to provide answers to some of the questions that you may have about CP, pregnancy and birth.

**Does CP affect fertility?**
There is currently no evidence to suggest that CP affects fertility. Research suggests it is uncommon for CP to be inherited. The risk of a mother or father with CP having a child with CP is not significantly different from that of any other person. Generally, there is no medical reason why a woman with CP should not have a baby, with no greater risk of miscarriage or premature birth. Pregnancy should have no lasting adverse effect on your CP.
Summary

• Women with disabilities live in our community and need our medical help

• While the accommodations related to Ob/Gyn disability care may be complex, they are achievable and women with disabilities deserve equal access and knowledgeable care

• Each patient is the provider’s best resource, start by asking them what they need

• There are many resources available on the internet for specific situations

• Patients often have to seek second or third opinions

• Patients and advocates should continue to demand inclusion in pregnancy care and research
Thank you!