Decision-Making Checklist:
Hypospadias

☐ 1. Overview
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Part 1: Overview

Let’s plan out how to cover the important topics about your care. We don’t expect to talk about everything in the first clinic visits. We need time to get to know each other. New questions come up as you get older and we don’t want you to feel pressured to understand everything right away. So let’s cover the basic plan and take it from there...

Things to cover today

- When (and how) were you and your family informed about your condition?
- What values do you or your family have that we should know about when talking about your body and sex?

Things to cover over time

- We would like to help you understand your anatomy and talk with you about puberty. At some point, you will be asked to talk to us without your parents in the room.
- A discussion about your urinary and sexual health is important.
- We would like to help you talk with and navigate this with family and friends.
- It is essential to meet another patient with your same condition.

How do you make decisions?

What big decisions have you made already in your life and with your body? What amount of information suits you?

- I want to know the basics.
- I want to know more than the basics.
- I want to know all the information.
- It doesn’t really matter much to me right now.
Part 2. Preferred Words List

We want to know how you would like to talk about your body. Here are some words we can use:

**How would you like for us to refer to your external genitalia?**

- I prefer to call it my “penis”
- I prefer to call it my “urethra”
- I prefer to call it my “pee hole”
- I prefer to call them my “testicles”
- I prefer to call them my “balls”
- I prefer to call them my “private parts”
- It doesn’t matter to me what words you use
- I’d prefer to call it something else

**How would you like for us to refer to your condition?**

- I’d prefer to call it “my condition”
- I’d prefer to call it “hypospadias”
- I’d prefer to call it my DSD (disorder of sexual development)
- I’d prefer to call it my intersex condition
- It doesn’t really matter to me what you call it
- I’d prefer to call it something else
Part 3: Topics that will come up as we get to know you...

Do you want to talk more about these issues?
- Not today
- At some point
- I’d like written materials or website references
- I’d like to talk privately

What might be different than if I didn’t have this condition?

1. Sexual health
   - Is there a difference with the appearance of my penis?
   - Will I experience difficulties with getting or keeping an erection?
   - Will I be able to experience sexual pleasure?

2. Urinary health
   - Will I be able to pee standing up?
   - Will I spray when I pee?

3. Reproduction potential
   - Will I be able to father children naturally?
   - Will I need special medical treatment or surgery to be able to father children?

4. Genetics/Genes/Chromosomes
   - What do we know about how my body developed as a baby?

5. Friends and family
   - What are the words I can use to talk to others about my condition?

6. What are risks and benefits of surgery?

7. My thoughts about my condition
Part 4. Patient Question List

Each patient should know what questions to ask. We can help you find the answers over time.

1. How common is hypospadias?
2. What does the genital exam entail and how often will you perform this?
3. If and when I need any additional genital surgery, what are the benefits vs risks?
4. Will I be able to father a baby?
5. Will my baby be affected by my condition?
6. Will I be able to experience sexual pleasure?
7. Will I have problems with erections?
8. Will I have normal genital sensation?
9. Will I have problems urinating (peeing)?
10. Will I need surgery on my testicles too?

Where can I go to learn more?

- http://heainfo.org/
- http://www.accordalliance.org/
- www.dsdfamilies.org
- www.interactyouth.org
- www.aiclegal.org
Part 5. Genital Surgery Options

Now that you have had a chance to review many of the important issues, we can look at the issue of management of your genitalia. This is a complex topic and we want to make sure you know as much as possible before deciding on a treatment plan.

1. **No treatments at all**
   a. Can I change my mind?
   b. Will I be able to have sex?
   c. Will I have problems having babies?
   d. Will I have problems urinating (peeing)?

2. **Primary hypospadias repair**
   a. May require a 1 stage or 2 stage procedure
   b. Will require a urethral catheter for 7-14 days after surgery
   c. May go home the day of surgery or spend 1 night in the hospital

3. **Re-do hypospadias repair/repair of complications**
   a. May require a 1 stage or 2 stage procedure
   b. May require using tissue from the inside of the lip or cheek (called buccal mucosa) to help reconstruct the urethra
   c. 1 day in the hospital
   d. Will require a urethral catheter for 7-14 days after surgery

4. **Surgery for undescended testicles**
   a. Can be done open or laparoscopically depending on the location of the testicles
   b. May be done at the same time as the hypospadias repair or at a separate surgery
   c. Sometimes the testicles are too high in the abdomen or are abnormal and need to be biopsied or removed

**Here are things for us to think about...**
- Have you done enough research?
- Have you had a chance to talk to your providers one on one?
- Have you used any support resources?
- Have you asked all of the questions you want before making a decision about surgery?

This condition is *part of your body*—it doesn't have to define you. A person's condition doesn't change who they are—it's a background pathway that helped you to grow and develop as you have.

Now, it's up to you and your family to decide what your condition means and how you want to make sense of that pathway, how to discuss it, and what part it will play in your life.