



PARENTS' GUIDE

Caring for your intersex child

A practical guide for parents from birth through childhood

General information for families



Your child needs love, safety, good health care, and the chance to grow as themselves.

Learning that your child is intersex may feel unexpected, and you may have many questions. This is natural. You do not need to have all the answers today.

This guide will help you understand what intersex means, make informed decisions, and support your child with confidence and care as they grow.

What does intersex mean?

Intersex is an umbrella term used for natural variations in a person's sex characteristics. These may involve the genitals, reproductive organs, hormones, chromosomes, or a combination of these characteristics. Chromosomes carry genetic information, while hormones are chemical messengers that help the body grow and function.

Some variations are noticed at birth, while others become apparent later in childhood, puberty, or adulthood.

Health workers may use terms such as *"Differences of Sex Development"* (DSD). If unfamiliar words are used, ask the health team to explain them clearly. Intersex does not mean a child has two complete sets of reproductive organs. It also does not determine who your child will be attracted to or how they may describe their gender as they grow.

Some things that are true for most intersex children:

Intersex children can live fulfilling lives and each deserves dignity, support and freedom from discrimination regardless of their health needs.

Being intersex is a natural variation in human development. While some intersex variations may involve health conditions that require medical care, being intersex itself is not something to fear or be ashamed of.

Being intersex is not a curse, a punishment, or evidence of wrongdoing by you or your family. Intersex variations occur in all countries, communities, and cultures.

What to do in the first days:**Welcome and care for your child**

Hold, comfort, and feed your child as advised by your health worker. Focus on bonding with your baby and meeting their everyday needs.

Do not blame yourself or your partner. Being intersex is not caused by something you did or failed to do.

Arrange a prompt medical assessment

Ask a qualified health worker to examine your child and arrange referral to a children's specialist if needed. A hormone specialist may also be involved.

Some children have hormone or salt-balance conditions that need urgent treatment. Others are completely healthy. Appearance alone cannot tell whether treatment is needed.

Ask for clear explanations

Tests may include blood tests, chromosome tests, hormone tests, or an ultrasound scan. Ask:

- Why is this test needed?
- What information will it provide?
- When will the results be ready?
- Who will explain the results to us?

Keep copies of test results, clinic notes, and care plans in one safe place.

Get emergency help if your child becomes unwell

Go to the nearest emergency health facility immediately if your child has:

- Repeated vomiting
- Poor feeding
- Marked weakness
- Unusual sleepiness
- Fewer wet nappies than expected
- Difficulty breathing
- Collapse or unresponsiveness

Do not wait for test results or the next appointment.

Some hormone-related conditions can cause dangerous salt loss and dehydration and require urgent treatment.

Making careful care decisions**Ask questions and make a plan with your child's health team**

Care should be based on your child's individual needs. Most intersex children do not need immediate surgery. Decisions about medical interventions should be guided by your child's health needs, the available medical

evidence, and respect for their future autonomy and choices.

Your role is to understand the options, ask questions, and help protect both your child's present health and future wellbeing.

Separate urgent treatment from procedures that can wait**Urgent medical care**

Urgent medical care is treatment needed to address a current threat to health, such as:

- Serious hormone deficiencies
- Dangerous salt loss
- Problems that prevent urine from passing normally

Essential treatment should not be delayed.

Ask the healthcare team to explain the condition, the risks, and the treatment in clear language.

Non-urgent procedures

Some procedures may be suggested primarily to change the appearance of genitalia rather than address an immediate health concern.

Do not feel pressured to make irreversible decisions because of fear, embarrassment, family expectations, or social pressure.

Seek independent medical advice whenever possible.

Where there is no urgent health need, consider delaying medically unnecessary irreversible procedures until your child is old enough to participate meaningfully in decisions affecting their body and future.

Take these questions to the appointment

- What have you discovered so far?
- What is still uncertain?
- Is there an immediate health concern?
- What could happen if we wait before making this decision?
- What options are available, including monitoring without surgery?
- What are the short-term and long-term risks of each option?
- Could treatment affect sensation, urination, fertility, or future choices?
- Will additional operations or lifelong medication be needed?
- Can you provide written information?
- Can we have time to think about our decision?
- Can we seek a second opinion?

Before you leave the health facility

Ask for a written care plan that includes:

- Medicines and doses
- Follow-up appointments
- Warning signs to watch for
- Emergency contact information

If your child needs hormone replacement therapy, ask for clear instructions about illness, vomiting, emergencies, and missed doses.

Give medicines only as prescribed. Never stop or change treatment without medical advice.

Ask how the health team can support decisions regarding registration documents and recording your child's sex.

If the diagnosis remains uncertain, ask:

- What decisions can safely wait?
- What registration procedures apply locally?
- What support is available while information is still being gathered?

A registration decision should never be treated as a reason to carry out unnecessary surgery.**Protect privacy during care**

Ask why each examination is necessary and who needs to be present.

Limit repeated genital examinations whenever possible.

Before photographs are taken:

- Ask why they are needed.
- Ask how they will be stored.
- Ask who will have access to them.

You can refuse photographs that are not medically necessary.

As your child grows, explain examinations beforehand and involve them in decisions as much as possible.

Being honest with your child

Children generally cope best when they are given truthful information in ways they can understand.

Toddlers (2-5 years)

Use simple names for body parts and reinforce that everybody is different and valuable.

School-age children (6-11 years)

You might say:

"You were born with a body that's a little different inside. Many people are. That's why we visit the doctor sometimes."

Teenagers (12+ years)

Provide fuller information, access to medical records, and meaningful involvement in healthcare decisions.

Some intersex young people may need hormone treatment during puberty, making early conversations especially important.

Never allow your child to discover important information accidentally.

Support your child through honest, age-appropriate conversations that respect their readiness, safety and privacy while ensuring they have access to truthful information about their body and medical history.

Helping your child feel secure**Make home a place of acceptance and honest conversation**

Your child's greatest source of strength is often the support they receive from family.

Create an environment that communicates:

- You are loved.
- You belong.
- You can ask questions.
- Nothing about your body makes you less valuable.

Give ordinary care and everyday opportunities

Continue with:

- Feeding and nutrition
- Immunizations
- Play
- School
- Friendships
- Routine health care

Follow any additional medical advice specific to your child's situation.

Allow your child to explore interests, talents, and activities without pressure to prove they are a boy or a girl in a particular way.

Their body does not define their potential, worth, or ability to succeed.

Talk openly and protect your child's privacy

Use simple and truthful language over time.

You might say:

"Bodies grow in different ways. You were born with a difference in how some parts of your body developed. You have done nothing wrong, and you can always ask me questions."

Avoid shame, frightening labels, or making your child feel responsible for keeping secrets.

Share personal information only with people who genuinely need it for your child's care, wellbeing, or safety.

As your child grows, involve them in decisions about what information is shared and with whom.

Do not post genital photographs or medical records online.

Privacy means protecting your child's personal information from unnecessary disclosure. It should never mean keeping important information from your child about their own body, health, or future.

What you can say to relatives

"Our child has a variation in sex development. We are receiving medical advice and support. We appreciate your support and ask that you respect our child's privacy."

Challenge teasing, blame, rumours, and discrimination. If bullying occurs, work with trusted teachers and school staff to create a safety plan while sharing only the information that is necessary.

Plan ahead and find support

Before puberty, ask the healthcare team:

- What changes should we expect?
- Will treatment be needed?
- Is additional emotional support recommended?

Fertility varies between different intersex variations. Do not assume that your child will or will not be able to have children in the future.

Listen respectfully to how your child describes themselves and seek supportive counselling when needed.

You deserve support too

Caring for a child with a newly identified intersex variation can bring questions, uncertainty, and emotional stress.

Seeking support is a sign of strength, not weakness.

Consider support from:

- Counsellors
- Social workers
- Trusted family members
- Parent support groups
- Intersex-led organisations and family networks

Choose people who respect confidentiality and do not pressure you into medical decisions.

If specialist care is far away, ask your nearest health facility for support with referral arrangements.

Key messages to remember

- Your child is first and foremost a child who deserves love, care, dignity, and respect.
- Being intersex is a natural variation in human development.
- Some intersex variations require medical attention, but many do not involve urgent health concerns.
- Do not rush into irreversible decisions because of pressure, fear, or stigma.
- Ask questions and seek clear information from qualified health professionals.
- Protect your child's privacy while helping them understand their body and health.
- You and your child are not alone. Support, information, and community are available.

Write down your next steps

Health worker or clinic

Contact number

Next appointment

My next question

A final word

Every intersex child is unique.

No guide can answer every question, and you may need time to learn and adjust. What matters most is that your child grows up knowing they are loved, respected, and supported.

Your child does not need to be "fixed" to be valued, included, or worthy of belonging.

With accurate information, appropriate healthcare, supportive relationships, and informed decision-making, intersex children can grow into healthy, confident, and fulfilled adults.

For more information or support, contact:



Email: codirectors.sipdug@gmail.com



Website: www.sipdug.org



Facebook: [SIPD_Uganda](https://www.facebook.com/SIPD_Uganda)



X: [SipdUganda](https://twitter.com/SipdUganda)

Your child's healthcare team remains the best source of advice about your child's specific health needs and circumstances.

