

When and how to tell your child they are HIV positive

As more children born with HIV survive into adolescence, parents face a difficult question: when and how should they tell their child about their status? Through real-life stories and expert guidance, we explore the delicate journey of disclosure, its benefits, and the challenges Ugandan families face.

BY ELVIS BASUDDE KYEYUNE

Twenty-two-year-old Justice Namutebi from Mpigi District first tested HIV-positive in 2015 and began receiving antiretroviral therapy (ART). When she later became pregnant, the long distance to the nearest health centre caused her to miss many antenatal services, including essential interventions to prevent mother-to-child transmission of the virus. As a result, her baby girl was born with HIV.

As her daughter grew, Namutebi struggled with a difficult question: should she tell her child that she was born with HIV? By the age of nine, the girl was naturally curious. "Mum, I am healthy. Why do I have to take medicine every day? How come other children don't?" I have seen you take med-

icine too. What sickness do you have?" she asked repeatedly.

"It feels like living with a ticking clock," Namutebi explains. "You know that sooner or later, your child will ask questions that you cannot avoid. But you worry about how it will affect their happiness, their sense of self, and even their relationship with you."

This dilemma is not unique to Namutebi. Paediatric HIV remains a significant challenge across Uganda and Sub-Saharan Africa. According to UNAIDS, approximately 3.3 million children under the age of 15 are living with HIV globally, with 2.9 million in Sub-Saharan Africa. In Uganda alone, about 95,000 children under 15 are living with HIV, which represents 0.5 percent of children in this age group.

Why disclosure matters

Experts emphasise that children who know their HIV status tend to take their medications more regularly and achieve better health outcomes. Dr Joshua Tamale from the Joint Clinical Research Centre (JCRC) states that disclosure helps children understand their condition, actively participate in their treatment, and take ownership of their health.

"It is not just about knowing; it is about empowering them to make choices that will keep them healthy and protect others," he says.

Beyond physical health, understanding their status helps children seek social support, develop coping skills, and engage in safer behaviours to prevent HIV transmission. Disclosure also fosters a sense of responsibility for their well-being and enables children to make informed decisions about their lives and relationships.

PAEDIATRIC HIV: WHAT PARENTS MUST KNOW

- Children living with HIV can grow up to lead normal, fulfilling lives. With proper treatment, regular care, and adherence to antiretroviral therapy, they can attend school, play sports, and pursue careers just like any other child. Nutrition also plays a critical role in their health. A balanced diet rich in proteins, vitamins, and minerals supports immune function and can improve the effectiveness of treatment, reducing the risk of complications.
- Mental health is another important consideration. Children with HIV may struggle with anxiety, depression, or feelings of isolation. Regular counselling, check-ins with mental health professionals, and support groups can provide emotional strength and help them navigate the challenges of growing up with a chronic condition.
- Family and community support are equally vital. Extended family members, community groups, and faith-based organisations can reinforce treatment adherence, provide guidance, and offer emotional reassurance. In recent years, innovative tools such as storytelling, games, and interactive apps have been introduced to help children understand their condition and treatment in a child-friendly and engaging way.

Timing is everything

The main question most parents ask is: when should a child be informed about their HIV status? The World Health Organisation (WHO) recommends that the process of disclosure should begin gradually when children reach school age. Uganda's Ministry of Health suggests starting this process between the ages of 10 and 12. However, it emphasises that each child is different, and parents should consider their child's understanding and emotional readiness.

If a child is not ready, it is crucial to provide gradual preparation and continuous support. Parents are encouraged to approach the conversation slowly, using language that the child can understand, and allowing them time to process the information.

The parent's challenge

Even with these guidelines, many parents feel hesitant. They often fear the stigma that could arise if others learn about either the child's or their own status. There is also concern about upsetting the child or damaging family relationships. Richard Sserunkuuma, the Executive Director of Positive Men's Union, says many parents avoid disclosure for years due to fears of confrontation or potential rejection from the child.

Parents might also struggle with how to explain HIV in an age-appropriate way. Some believe keeping the diagnosis a secret will protect their child's happiness. However, experts warn that delaying disclosure can

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lead to negative consequences such as children hiding their medications, lying about taking them, or experiencing anxiety and confusion.

Real stories, real success

Despite these challenges, many families have successfully navigated the disclosure process. Harriet Birungi from Buyikwe District involved her son's teacher to help him understand his HIV status when he was 10 years old. She states: "It was not easy, but with support, he came to terms with his condition. Swallowing medicine is still a challenge, but at least he knows why it is necessary."

Patrick Bagemu from Bududa Town disclosed his daughter's status to her when she was eight. Although she initially cried, she eventually became an active participant in her treatment. Bagemu shares: "She reminds me to take my medicine on time and helps us stick to a schedule. It has become a shared responsibility."

Many health facilities also use trained expert clients and paediatric counsellors to support families through the disclosure process. Flavia Kyomukama, the Executive Director of the National Forum of People Living with HIV and Aids Networks in Uganda, emphasises that disclosure remains a sensitive issue.

"Even though fewer babies are born with HIV today, there is an increasing number of adolescents who need to know their status. Delaying disclosure can cause serious psychological harm, leading children to hide their medications, lie about them, or, in extreme cases, attempt to run away or harm themselves."

Guidance and support

Cultural attitudes can also influence disclosure. Some caregivers feel children should be trusted to maintain confidentiality, while others worry about emotional consequences. Positive approaches stress that knowledge empowers children to take responsibility for their health and adhere to treatment.

Legally, the law requires parents or guardians to provide counselling before disclosure and ensure ongoing emotional support. Health workers and expert clients provide guidance on how to explain HIV in an age-appropriate manner and how to support the child emotionally during the process.

Parents are encouraged to seek counselling, approach disclosure gradually, and reassure children that knowing their status is not a sentence but a path to better health.

Looking ahead

For parents such as Namutebi, telling the child is painful but necessary. "Keeping it a secret only makes them anxious and confused. Once they know, they can take control of their health, make safe choices, and understand the medicines that keep them alive," she says.

As World Aids Day approaches, health experts stress that disclosure is crucial in empowering children living with HIV. It ensures treatment adherence, promotes mental well-being, and helps children understand how to protect themselves and others. With the right guidance and support, parents can navigate this difficult journey, giving children the knowledge and confidence to live more informed lives.

