



**Elizabeth Glaser
Pediatric AIDS Foundation**
Fighting for an AIDS-free generation

Caregiver Dialogues

Disclosures

The Start:

Sharing your child's HIV diagnosis with them can be difficult, but there are experienced people to help you throughout the process. Going through this can be scary, yes, but also liberating. It can quite be helpful to see different scenarios of initiating the conversation, as demonstrated in the storyline below:

Lou and Aya

Lou is **Aya's** mother. Aya just turned ten, and at the last clinic appointment the counselor and Lou discussed that it was time to begin sharing more information with Aya about her health, her body, her HIV diagnosis, and the reasons for taking medications and coming to the clinic regularly.

Lou has been worried that sharing about HIV will upset Aya. She also believes that Aya may not fully understand what living with HIV means and may share her status with other people who might hurt her and could stigmatize her and the whole family.



Lou and Aya at the clinic

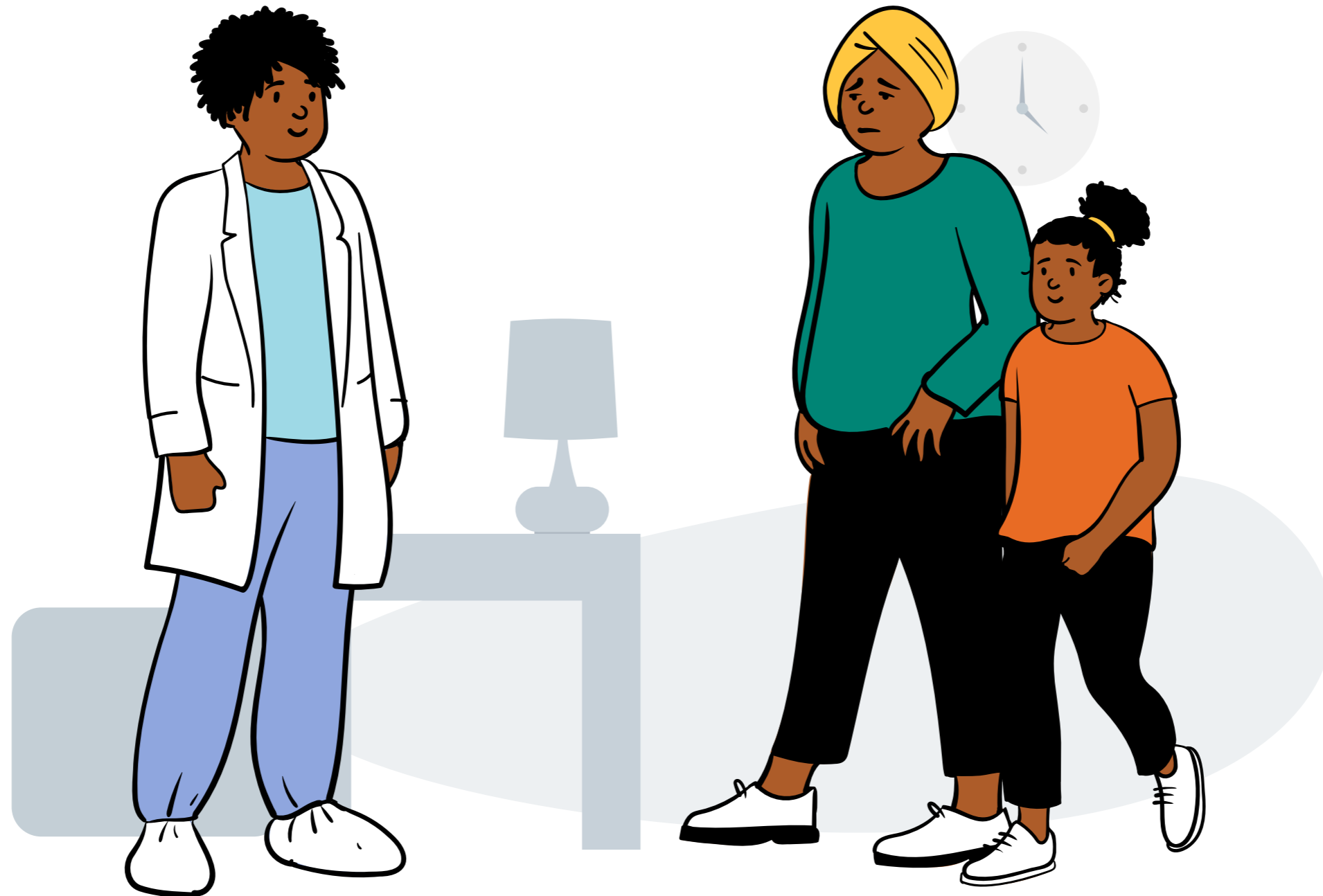
Counselor – Good afternoon! How are you, Lou and Aya?

Lou – Good, thank you.

Aya – I'm feeling good.

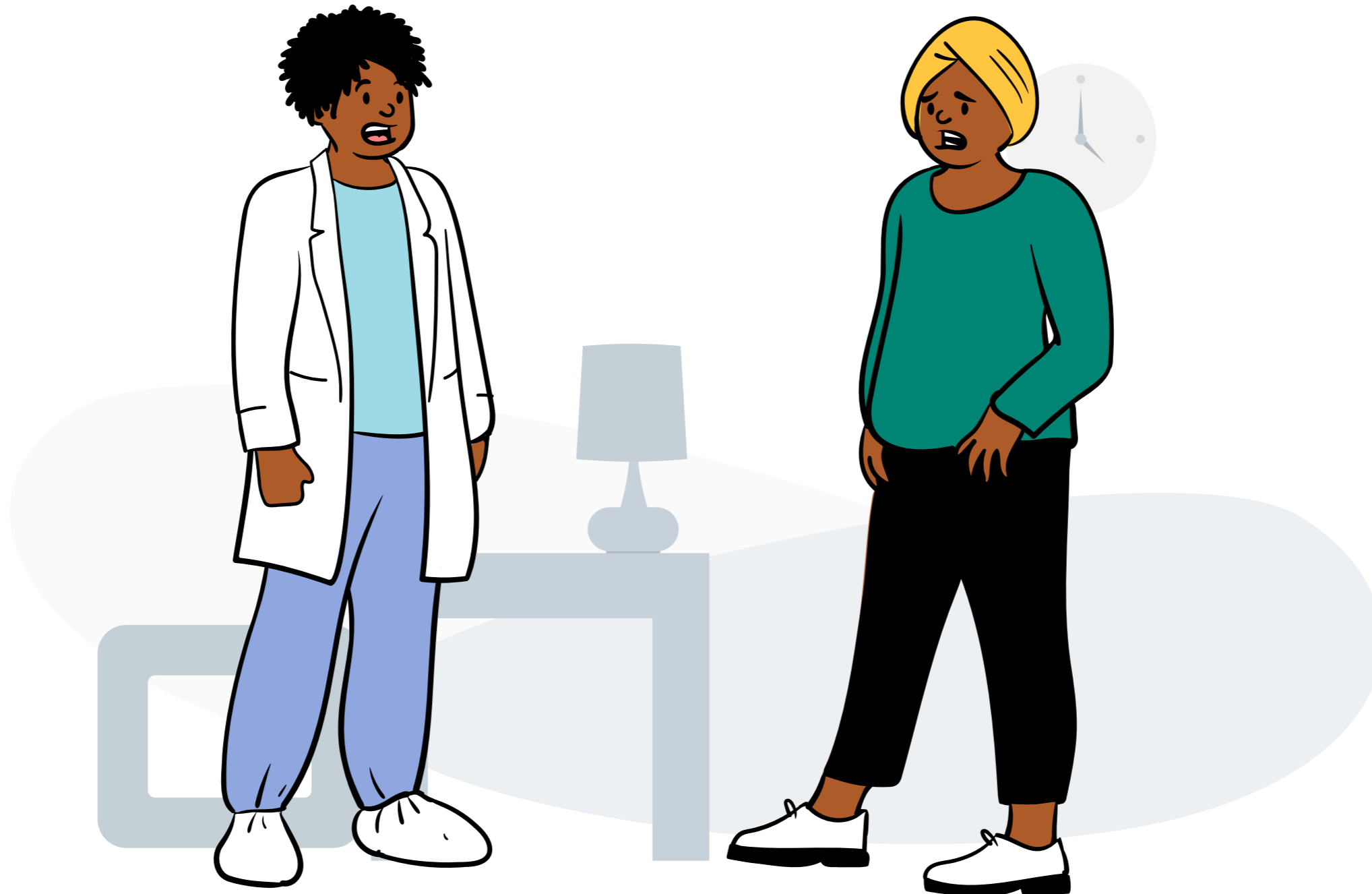
Counselor – I'm glad to hear that Aya. I'm going to speak to your mother for a minute, okay? There are some games in the youth corner if you want to play.

Aya exits the room.



Counselor – Lou, it is time to start talking to Aya about her health and about her HIV diagnosis. We will do it together.
How are you feeling about that?

Lou – No, I am not ready, and don't believe Aya is ready either.



Counselor – I know it's a scary thing to do and we always want to protect our children, but Aya is growing up and learning more about life. She is probably already asking herself why she is taking pills and coming to see us. Her body is also about to change as she develops into a young woman. It is important for her to be able to start to understand her own health needs and to learn how to take care of herself.



Counselor – I am here to help you have these discussions with Aya. We will start slowly by sharing more about her health and eventually, when she is ready, we'll tell her about her HIV. What do you think?

Lou – I don't think I can do that. I am her mother, and I feel guilty for passing the virus to her. She will blame me and feel upset. She might also share her HIV diagnosis with other people who will negatively judge her and the whole family. I love my daughter and want to protect her.



Counselor – I fully understand your concerns. Your daughter loves you too, and we will help her understand. You are a good mother and only want the best for her. We will teach her to be strong and resilient and to take good care of her health. With your permission, I'm going to invite Aimee, who is an experienced caregiver living with HIV who works with this clinic, to share her experience.



In a private room in the clinic

Aimee – Hello Lou, I'm glad we could meet to talk. The counselor shared with me that you are getting ready to start gradually sharing the HIV diagnosis with your child.

Lou – Nice to meet you, Aimee. I'm still not sure about telling Aya. She's not ready.



Aimee – I understand. I felt like that a few years ago with my boy Yao. I thought he was too young, that he wouldn't understand, or that he would tell other people who wouldn't understand and stigmatize him.
Are you feeling the same?

Lou – Yes, that's right.



Aimee – The hardest part is realizing that talking with your child about their HIV diagnosis and the reasons they take medicine helps them to understand why they keep coming to the doctors. It allows them to stop worrying about the unknown and helps them to become a strong, resilient person capable of managing their own care.

Lou – What do you mean?



Aimee – Part of growing up is learning more about the world and yourself. For parents and guardians, it means protecting our children while also giving them space to grow and learn on their own. Keeping a child’s HIV diagnosis a secret from them creates more uncertainty and can make them feel insecure. As caregivers, we want to give our children opportunities to develop skills to be successful later in life—and part of that starts now, with sharing Aya’s HIV diagnosis with her and helping her learn how to stay strong.

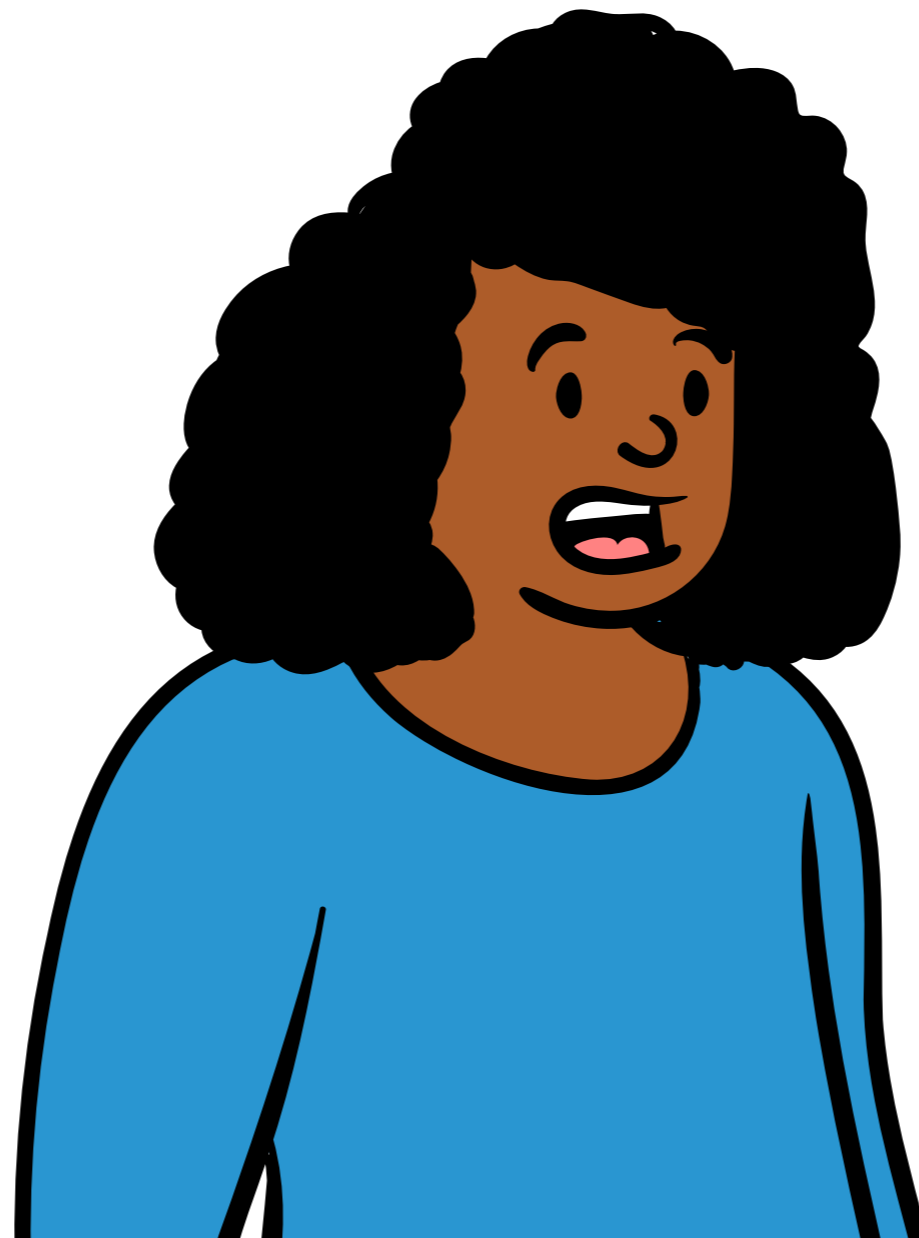


Aimee – I am a mother living with HIV, and from personal experience, I can say that this was not easy for me either. But after sharing my son’s status with him I felt relieved, and most importantly, it helped him to grow. We no longer have secrets between us.

Lou – How did you do it? How did it go with him?

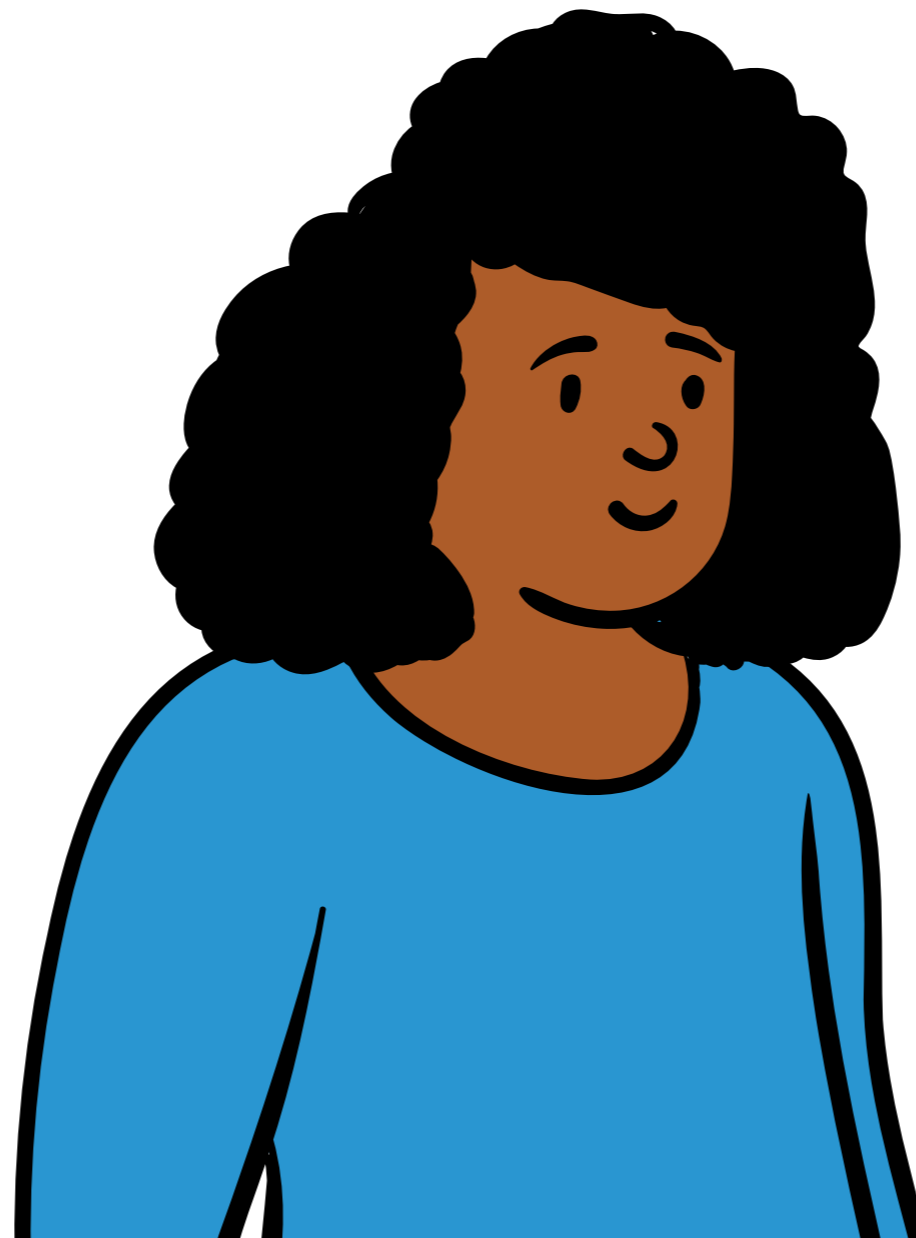


Aimee – I worked closely with a counselor to gradually share more information with Yao at each clinic visit so that he could learn more about his body, blood cells, and health. After a few conversations, he started to ask more questions, and the counselor and I decided it was time to tell him about living with HIV. I wanted to do it in our home with just me and him — but that decision is up to you. You can do it anywhere and even have the counselor be there to support you or answer questions. We can also help you prepare for the conversation if you decide to do it by yourself at home.



Aimee – I sat down with my son when we were alone in our home, and I told him that he had HIV. He was surprised and didn't understand everything, but we talked through his concerns. Over time, he has come to understand what it means. I explained to him that I love him and that passing the virus had nothing to do with me caring for him. We also linked Yao with peer support groups, where he met other children and young people living with HIV. It helped him a lot to understand he was not alone, and he also learned from hearing about their experiences of in living positive lives

I am confident you can do it as well! We will be supporting you, and I assure you that Aya will be strong and will learn how to take care of herself. You will be proud of your daughter.



Lou – Okay, I guess we can start slowly sharing more information with her.

Aimee – Exactly! Slowly build up the information, and then share her status with her when you are ready.



Lou – Thank you, Aimee. It was good to talk with you, and it has been helpful to hear from someone who has gone through this. It is also good to hear that your boy is doing well.

Aimee – I am here if you need advice. However hard it seems now, you and Aya are strong women and you both can do it. It will be better for both you and Aya in the long term. I wish you success and good health.
Let us stay in touch.



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