

If someone were to see David* sprawled out on the hotel room bed, exhausted from a long day out and playing myspace on someone's iPhone, he would look like a normal 16-year-old boy. And in almost every way, he is. David plays basketball and football for his high school in Chicago as well as holds down a part time job at the local 7-11. He is desperate to get his license, like every 16-year-old and can't wait to buy his own car. David is active in his school's athletic programs and plans on playing both basketball and football in college. In every way David is like every other 16-year-old boy from Chicago, except that he has HIV.

HIV entered David's life without him even having a say so about it. He was born to a HIV positive mother who in turn, without knowing, infected him with the disease.

"HIV first came into my life when I was born," David said. "A couple hours later my mom died. HIV/AIDS has impacted my life cause if my real mom had taken her medicine I would not have HIV."

This disease that has infected David has also affected every aspect of his life. The doctor's appointments come like clockwork every three months along with blood work and sometimes more medication. The medication must be taken strictly at 8 a.m. and 8 p.m. every day in order to be effective. David cannot tell a soul that he has HIV because of the social stigma that surrounds the disease.

"Since I was born my life has been different, sometimes it seems like it's a disaster," David said. "My dad's wife raised me and I consider her my mom. I was six years old when I learned that I had HIV."

Most children who suffer from HIV/AIDS have contracted the disease just like David. Without even knowing, kids across the globe are being infected with HIV/AIDS by the sheer fact that they are born. HIV/AIDS can be transferred from person to person three ways: from mother to child during childbirth or breastfeeding, through sex (oral, anal or vaginal) and through blood-to-blood contact. These are the only ways that HIV/AIDS can be transferred.

Most kids like David become HIV positive the first way, either during childbirth or breastfeeding. Unfortunately, the stigma surrounding HIV/AIDS does not allow youth (or anyone for that matter) to live their lives normally. Those who are positive live their lives in fear that someone will find out their status. Once that happens they can be kicked out of church, school or work. Communities have been known to shun those suffering from the disease.

David undergoes the constant struggle between who he wants to be and who his HIV forces him to be. To David, when he thinks about his HIV status all he can think about is the control that is had over his life. That's one reason why David decided to stop taking his medications a year ago this May.

A common misconception about HIV/AIDS medications is that they make everything better. When someone has a headache, an Excedrin or Advil will usually do the trick.

Michael Viscariello is a social worker at Children's Hospital Los Angeles and gets a first-hand look at the struggles children have with taking their HIV/AIDS medications.

“I do not think that society has a very good understanding of HIV,” Viscariello said. “We rarely hear about it HIV anymore, in the United States, anyway. People think that the problem has gone away; that you can take a pill and you are cured. They do not understand all of the side effects from these medications. This is the message that we have received. So usually people are still either very afraid of HIV/AIDS or they think it is not something to worry about.”

For teens like David, these restrictions cause great inconveniences. According to Nichole Wiener, a registered nurse in Omaha, Nebraska, who works with children suffering from this disease, HIV medications are often cumbersome for children to take.

“There are several kids on a med called Sustiva, which makes them very tired and can cause bad dreams,” said Wiener. “A few have issues with nausea and diarrhea.”

In addition to the physical problems that arise when taking medications, they can also cause several other side effects.

“I would like to separate this problem in two stages: a) Children under 9 mostly do not have problems taking the meds since their caregivers are in charge of their care and b) Once the child are more independent/self sufficient and with many years taking meds, they become getting tired of taking their meds and start to have poor adherence. Other factors like acceptance, puberty, new relationships, having boyfriends/girlfriends, school issues” said Rosalva Vasquez, family advocate for the University of California at San Diego Mother, Child & Adolescent HIV Program.

“Psychosocial issues are a deterrent in the whole meds adherence spectrum.”

David is like any other young person with HIV. He does not tell anyone that he is positive. "I don't feel open about that. That something that you just don't tell people. You just don't go around telling people that you have HIV; that's just not smart. It's not that I am ashamed, it's just something that you don't tell nobody about," he said.

David, in his quest to feel free from the harness of his HIV medications, decided to stop taking them when he was 15.

HIV medications are often more trouble than just the side effects. The medications act as a daily reminder to young people like David that they have an incurable disease. In addition, HIV medications must be taken at a very strict regimen. In order for the meds to work properly, they must be taken either every 12 or 24 hours, precisely. If a dose is missed or taken it later than instructed, the virus has that much more time to begin replicating in one's body.

This means that HIV positive youth may have to take their medications when their peers are around.

"It's just my vitamin" is the most common response HIV positive youth give when their friends ask them about their meds. However, sometimes the pressure of being a teen and wanting to fit in with your friends causes young people to miss doses; or in David's case, to stop taking meds all together.

Another problem that arises with HIV/AIDS medication is that the meds are not made specifically for children.

“Currently young people take the same meds as adults, just at lower doses,” Wiener said. “Giving children adult doses can cause serious and chronic conditions such as encephalopathy, which is a swelling of the brain. Many of the meds have been made at lower doses, but some of our campers still take an adult dose pill, cut in half. Anytime you are cutting pills in half you run a major risk of a mis-dose or changing the way the med reacts in the body. Several of the campers take a med called Viread, and their dosage requires them to take 2/3 of the pill; obviously difficult to guarantee the correct dosage.”

Katie Townsend is a registered nurse in Lincoln, Nebraska, and volunteers with Camp Kindle in the summers. Camp Kindle is a summer camp for youth who are either infected or affected by HIV/AIDS. Townsend has personally seen the struggles that kids have with taking their medication.

“One camper in particular stands out,” she said. “One young camper was suffering from very vivid nightmares as a side effect to one of his medications. The nightmares were terrifying for him and he was afraid to go to bed at night. Eventually the doctors were able to attribute this to his medications and prescribed sleeping pills for the boy so he would sleep through his nightmares and not remember them in the morning.”

HIV/AIDS meds are saving the lives of thousands of children each year; but it comes at a price. “The biggest struggle that children with HIV face is taking medications,” Viscariello said. “Taking medications usually involves a lifelong commitment. It is difficult for small children to swallow these big pills or for them to take liquid

medications that taste horrible. They are required to take pills 1-2 times a day and consistently missing doses can lead to them becoming resistant to those particular medications. There are only a certain amount of combinations that are available to them. If they become resistant to all of the medications, then they are left without any treatment options, thus a commitment to perfect adherence is very important.”

David felt that the medicine he had to take to stay alive was simultaneously bringing him down. The pressure to take his meds on time and consistently became too much for him. He said that it started by skipping a dose here or there and then progressed into not taking the medication at all.

“It’s not the taste, it’s nothing like that,” David said. “The medicine don’t make me feel bad or nothin’ anymore... I just got tired of it. I stopped taking my medication because I was angry. Honestly, if I’m being honest... I was trying to kill myself. That’s how frustrated I was at one time. I hate to say it, but I just said, “forget it” ... that’s how I felt.”

Pamela is a HIV-positive high school student who struggles with the adherence to taking her medication.

“For me it’s not so much that I get the side effects; it’s so annoying that I have to stop what I’m doing and take my meds,” Pamela said. “I might be doing my homework or, like, hanging out with my friends or doing something really good and I have to stop and take them. And then people ask and I lie, usually.”

David's doctor found out that he was no longer taking his medications because his viral load went up and his T-cell count went down. A healthy person, without HIV or AIDS, has a T-cell count of 1,000 to 1,200. Any number below 200 clinically diagnoses a person with full-blown AIDS. David now has 300 T-cells left to fight off any virus, including HIV, in his body.

David attends Camp Kindle in Fremont, Nebraska, every summer. There he gets to talk openly about his HIV status with other teens who are experiencing the same things as him. It was at Camp Kindle that David was pulled aside by one of the psychosocial team members to talk about why he was not taking his medications anymore.

"It was Camp Kindle that opened my eyes, and I realized that there was more to life than death," David said. "So I started taking my medicine again."

Today, David speaks around the country to teens about living with HIV. Though he would still never tell a soul in Illinois about his status, he does not mind educating teens from other states about the disease. He believes that education is the key to the end of the stigma surrounding HIV/AIDS. The more people know about how HIV/AIDS is spread, the less stigma there will be.

"Sometimes it scares me because I think sometimes that I could die, and I don't know when," David said. "The disease might just shut down my body. But I know that if I keep taking my medicine, I will live."

*David is not his real name.