

Checklist for clinics: What do young people living with HIV say they need? Amanda Ely: July 2015.

Knowledge and understanding:

Young people report that being told about their HIV at a younger age is preferable to them. They have more time to acquire knowledge and understanding of HIV and accept their diagnosis.

Providing an open environment to talk about HIV is important. When this is achieved at a younger age young people acquire greater confidence in their understanding of HIV, helping them to cope with HIV stigma.

“An open environment to talk about HIV helped my learning aged 8. I felt confident to tackle HIV stigma because I knew the facts.” (Young person with HIV; member of “Treat me Like This” Youth Guidelines Group).

Relationships:

Young people need to have a good established level of understanding of HIV to be able to ask further questions about their health. Re-visiting information on HIV already provided to ensure on going understanding is achieved is helpful. Information should be provided in manageable chunks and revisited. Always ensure there is an opportunity for a young person to ask any questions in relation to their HIV.

Young people highly value being able to build a relationship of trust with health professionals. It is important to try and establish consistency, long term relationships are helpful where possible. Having the opportunity for open conversations about HIV with these professionals.

Medical and personal information about HIV needs to make sense to the young person. Young people want to understand the context of HIV in their lives, they benefit where there is openness about HIV in their family context. Clinics can work with families to support them being able to hold open conversations with their children about HIV and how it has affected their family.

“Understanding my family story of HIV is really important- I am so confused”
(Young person with HIV; member of Treat me Like This Youth Guidelines Group).

What do young people find unhelpful about their clinical care?

Young people find it very stressful and unhelpful when health professionals become angry or apply a lot of pressure in relation to medication adherence. This affects the collaboration between the patient and their health team negatively.

“When my doctor gets angry with me if I miss a dose – it is really stressful, telling me I am going to die...”

“I will lie a bit about how many doses I have missed. I have had to because I feel under pressure from my doctor” (Young people with HIV; members of “Treat me Like This” Youth Guidelines Group)

Young people describe a critical need for empathy. To appreciate the challenges of a daily medication regime and in particular how pressurised this can feel during adolescence when young peoples lifestyles are taking them away from the home more. Young people describe a need for their health professionals to understand how emotional taking HIV medicine can be for the reminders of their HIV which many are struggling to accept.