

Disclosure Protocol Paediatric Clinic

Stage One: Meet with caregiver(s) involved in decision making process

- a. Ascertain whether caregiver(s) has planned for disclosure
 - i. When do you plan to tell the child/adolescent about his/her illness
 - ii. Get details: What age? What month?
- b. If caregiver(s) ready to disclose move to **Stage Two**
- c. If caregiver(s) not ready to disclose (and the child is under age 14):
 - i. Encourage caregiver(s) to begin to use words that can be built on later such as immune problems, virus, infection, germ
 - ii. Provide caregivers with reading material about the benefits of disclosure
 - iii. Strengthen caregiver(s) education and support; plan to check in with caregiver(s) at next scheduled appointment
 - iv. Let caregiver(s) know that should they decide to disclose you will guide them through the process and provide follow up support
 - v. Respect caregiver(s)' timing
 - vi. Strongly encourage the caregiver(s) not to lie to the child if he/she directly asks about HIV (unless there are significant identifiable safety concerns that would make disclosure unadvisable)
 - vii. Remind caregiver(s) to avoid disclosure during argument or in anger**

Stage Two: Have caregiver(s) think through how they want conversation to go

- a. Get feedback on child's anticipated response

- b. What messages do they want children to walk away with
- c. Encourage caregiver(s) to begin with “Do you remember...” – let the child be reminded of past events, medication, procedures before introducing new facts. You are just giving a name to something that already exists
- d. Have the caregiver(s) choose the place that is most comfortable to talk openly
- e. Provide caregiver(s) with questions child may ask so they are prepared with answers/ role-play question & answer session with caregiver:
 - i. How long have you known this?
 - ii. Who else has the virus?
 - iii. Will I die?
 - iv. Can I ever have children?
 - v. Who can I tell?
 - vi. Why me?
 - vii. Who else knows?
- f. Encourage the presence of people the child is most comfortable with – no strangers
- g. Your use of medical facts should be minimal – use words child can understand
- h. Remember silences as well as questions need to be accepted. Remind the child that nothing has changed except a name has been given to what he/she is living with
- i. The child needs to hear that he/she did not do anything wrong if he/she is asked to keep their status a secret.
- j. If the diagnosis is to be kept a secret, the child should be given names of people they can talk to. “You can’t tell anyone” may make child feel ashamed and guilty
- k. Provide journal or diary to child to record questions, thoughts or feelings

- I. Schedule follow up appointment within two weeks/ let caregivers know that they can request an earlier appointment if they wish

Stage Three: After Disclosure

- a. Individual and caregiver(s) follow up should be done two weeks after disclosure and again every two months during the first 6 months after disclosure. Assess impact of Disclosure, answer questions and foster support between child and caregiver(s)
- b. Ask child to tell you what he/she has learned about the virus. Address misconceptions where exist
- c. Assess changes in emotional well-being and provide family with information about symptoms
- d. Continue to support caregivers after they have disclosed diagnosis
- e. Remind parents that disclosure is not a one time event and that ongoing communication is needed.

Disclosure Policy Paediatric Clinic

1.0 Definition of Disclosure

- 1.1 Disclosure refers to the process through which a child/adolescent receives, and copes with information about his/her HIV status
- 1.2 Disclosure is a process as opposed to a one-shot dose of information. An individual proceeds through the process of disclosure throughout his/her lifespan. The Paediatric Team aims to offer patients and their caregivers' holistic psychosocial support through the length of their treatment, from diagnosis to medical management
- 1.3 The first point of disclosure is receiving the HIV diagnosis. Disclosure continues as SKT supports the child and his/her caregivers to increase their understanding of HIV and learn how the virus behaves in the body
- 1.4 There are three categories of disclosure status
 - Disclosed
 - Partially disclosed
 - Not disclosed

2.0 Categories of Disclosure: the following are the basic criteria which must be met for each category

- 2.1 Disclosed: The child/ adolescent
 - 2.1.1 is able to articulate that he/she is HIV positive
 - 2.1.2 can communicate that HIV is a chronic illness which can be treated and controlled but at this time cannot be cured
 - 2.1.3 can articulate the modes of transmission of HIV
 - 2.1.4 is aware of how he/she contracted HIV
 - 2.1.5 is knowledgeable of all precautions he/she must take to protect him/herself from re-infection

- 2.1.6 is knowledgeable of the precautions which must be taken to prevent transmitting the virus to others
- 2.1.7 is aware of HIV-related stigma and discrimination
- 2.1.8 understands how and when to take all required medication

2.2 Partially disclosed: The child/ adolescent:

- 2.2.1 is aware that he/she has a chronic illness, which can be treated but at this time cannot be cured
- 2.2.2 is aware that he/she takes medication to control the illness
- 2.2.3 is knowledgeable of some of the precautions (excluding sexual safeguards) which must be taken to prevent transmitting the virus to others
- 2.2.4 does not have a comprehensive understanding of the virus, how it is transmitted and the course of the illness

2.3 Not Disclosed: The child/adolescent:

- 2.3.1 is not aware that he/she is being treated for a chronic illness
- 2.3.2 believes that his/her illness is acute and may believe that a diagnosed opportunistic infection is the cause of his/her illness

3.0 Age of Disclosure

- 3.1 Patients should be recommended for partial disclosure by age 10
- 3.2 All patients must be disclosed by age 14

4.0 Disclosure Plan

- 4.1 Every child treated at SKT must have a disclosure plan included as part of their treatment plan
- 4.2 The disclosure plan is formulated after the initial psychosocial assessment by the SKT staff member who conducts the initial interview

- 4.3 The disclosure plan identifies the child/adolescent's disclosure status at the time of the psychosocial assessment and outlines a plan of action to increase the patient's knowledge of HIV and provide relevant psychosocial support

5.0 Legal and Ethical Responsibilities

- 5.1 The constitution of South Africa gives the child the right to basic health care services. If a child is 14 years or older, the child has the same right to confidentiality as an adult. A child of 14 years or older who consents to an HIV test has the right to keep his or her status private. SKT is bound by law to disclose the HIV status of a child who is 14 or older without the consent of his/her caregiver
- 5.2 SKT values the importance of caregivers to the functioning and adjustment of the adolescent and our aim is to include the caregiver in the treatment of the child/adolescent
- 5.3 Where caregivers are reluctant to disclose to children age 14 and older, the SKT staff will exhaust all means to facilitate their part in the disclosure process. However, if the Paediatric Psychosocial Team arrives at a consensus that it is the legal and ethical responsibility of SKT to disclose an adolescent's status, disclosure will be carried out without the consent of the caregiver
- 5.4 It is the right of the child to understand how an illness is affecting his/her body and it is our ethical responsibility to relate this information in a child-friendly manner

6.0 SKT staff involvement in the Disclosure Process

- 6.1 It is preferable that the primary caregiver(s) or a trusted, consistent adult(s) in the life of the child/ adolescent initially discloses to the child in a familiar non-threatening environment. SKT will only disclose to the child **if the above conditions cannot be met**

6.2 Where primary caregivers request and require support, SKT staff may be present to support the process