



CHILD DISCLOSURE

DISCLOSURE OF HIV STATUS TO A CHILD

What is HIV?



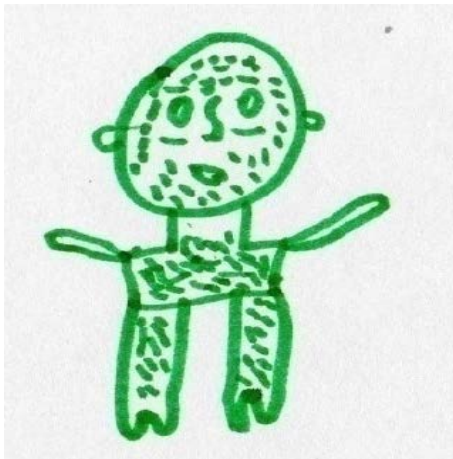
10-year-old boy



classer CE 1


par le sida qui a fait que
elle pensait il va a l'hôpital
docteur dit il ne peut rien et
il pleure et il va

He's crying because of AIDS. He went to the hospital and the doctor says he can't treat. He's crying and...



10-year-old girl

SOME QUOTES OF HIV+ CHILDREN


- “Mum tells me to take my medicines, if not I will die. She also tells me not to talk about it with anyone. If she says not to talk about it, it’s because it is AIDS” (Isabelle, 8)
 - “When the doctor gave the test results to my mum, I’ve seen her face...I understood” (Adama, 12)
 - “Mum’s gonna ask me how I got it.”
 - “Because of my skin problems, someone at school said I have AIDS.” (Dieudonné, 14)
 - “If I say I have HIV, the others will not play with me anymore.”
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LEARNING OBJECTIVES

By the end of this session, participants will be able to:

- Describe the concepts of disclosure & progressive disclosure
- List the benefits of child disclosure
- Identify why care-takers are reluctant to disclose the HIV status to their child

LEARNING OBJECTIVES (CONTD.)

- Describe the importance of communicating with the child about health and illness & disclosing the status to the child
 - Describe what and how to communicate and/or disclose the status to a child
 - Perform child disclosure sessions
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WHAT IS HIV DISCLOSURE TO A CHILD?


It is an ongoing process where a child learns about health, (unnamed) infection, treatment, and finally is told about his HIV status

Progressive Disclosure = Partial Disclosure → Full Disclosure


Partial: Fragmented information on what is happening in child's body, illness and need of treatment without mentioning the term HIV

Full disclosure: detailed and complete information using the terms HIV and AIDS

WHY DISCLOSE?

- Gives appropriate and accurate information to child in a way they can understand → Child feels secret and creates his own explanation (which can be worse than reality)
 - Engages children in their care, increased responsibility
 - **Improves treatment adherence**
 - Fewer psychological issues, confusion, fear, anxiety and depression
 - No risk of learning the truth from other sources
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WHY DISCLOSE? (CONTD.)

- Healthier relationships in the family
 - Promoting children's sense of self control and self-esteem
 - Assists children to make choices and decisions about issues which affect them and improve their quality of life
 - Helping both the child and family adopt a positive attitude
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WHY CARETAKERS ARE RELUCTANT TO DISCLOSE

Educational reasons:

- Not seeing the need, especially when child has few symptoms
- Belief that the child is too young and won't understand
- Belief that if the child doesn't ask questions, he doesn't realize what is going on
- Cultural habits (of little communication with child, of not seeing child as person that can take on responsibility)
- Not knowing how and what to communicate with child


WHY CARETAKERS ARE RELUCTANT TO DISCLOSE

Emotional reasons:

- Fear about immediate / long term reactions of child – wanting to protect the child of negative feelings, depression,...
 - Fear child will reject caretaker
 - Isolation or lack of support to help caretaker to take the decision to disclose
 - Difficulty to cope own illness (HIV+ care-taker)
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WHY CARETAKERS ARE RELUCTANT TO DISCLOSE

Emotional reasons:

- Fear of having to disclose own status (HIV+ care-taker)
 - Feeling a shame and guilt of having transmitted the disease (HIV+ care-taker)
 - Don't want to frighten child with possible future death of caretaker (HIV+ care-taker)
 - Child represents hope, non-disclosure keeps illness away
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WHY CARETAKERS ARE RELUCTANT TO DISCLOSE

Family related and social reasons:

- Familial or cultural taboo (sex, death,...)
 - Fear of sensitive or embarrassing / difficult questions of the child (on family history,...)
 - Beliefs about origin of HIV/AIDS (witchcraft, punishment)
 - Fear that the child won't keep the secret and will disclose to other people
- Health staff can be reluctant for the same reasons!

DISCLOSURE CAN BE CHALLENGING

- Not rare to see children expressing sadness, anger, depression, isolation: adaptive process also for children
 - When disclosed to early or in a bad manner, a child can disclose to others, without being aware of the consequences
 - Disclosure to adolescents can provoke intense emotional reactions such as anger, rebellion, denial,...
- but... keeping a secret for a long time brings a lot of difficulties and are more important than the temporary difficulties of telling them

WHEN AND WHO?

When:

- Partial disclosure can start as early as ~ 5 years old
- Full disclosure should be done before adolescence

Who:

- Parent/caregiver, a person the child trusts at the clinic (health worker)

PREPARING FOR DISCLOSURE

- **Is child ready for disclosure?**
 - Age alone is an unreliable indicator for “right” time to choose
- **Is parent/guardian ready for disclosure?**
 - If not ready: counselling should continue at each contact with the family
 - If ready: discuss and confirm with caregiver exactly what will be said to the child

WHEN?

PARTIAL DISCLOSURE (5 to 9 years):

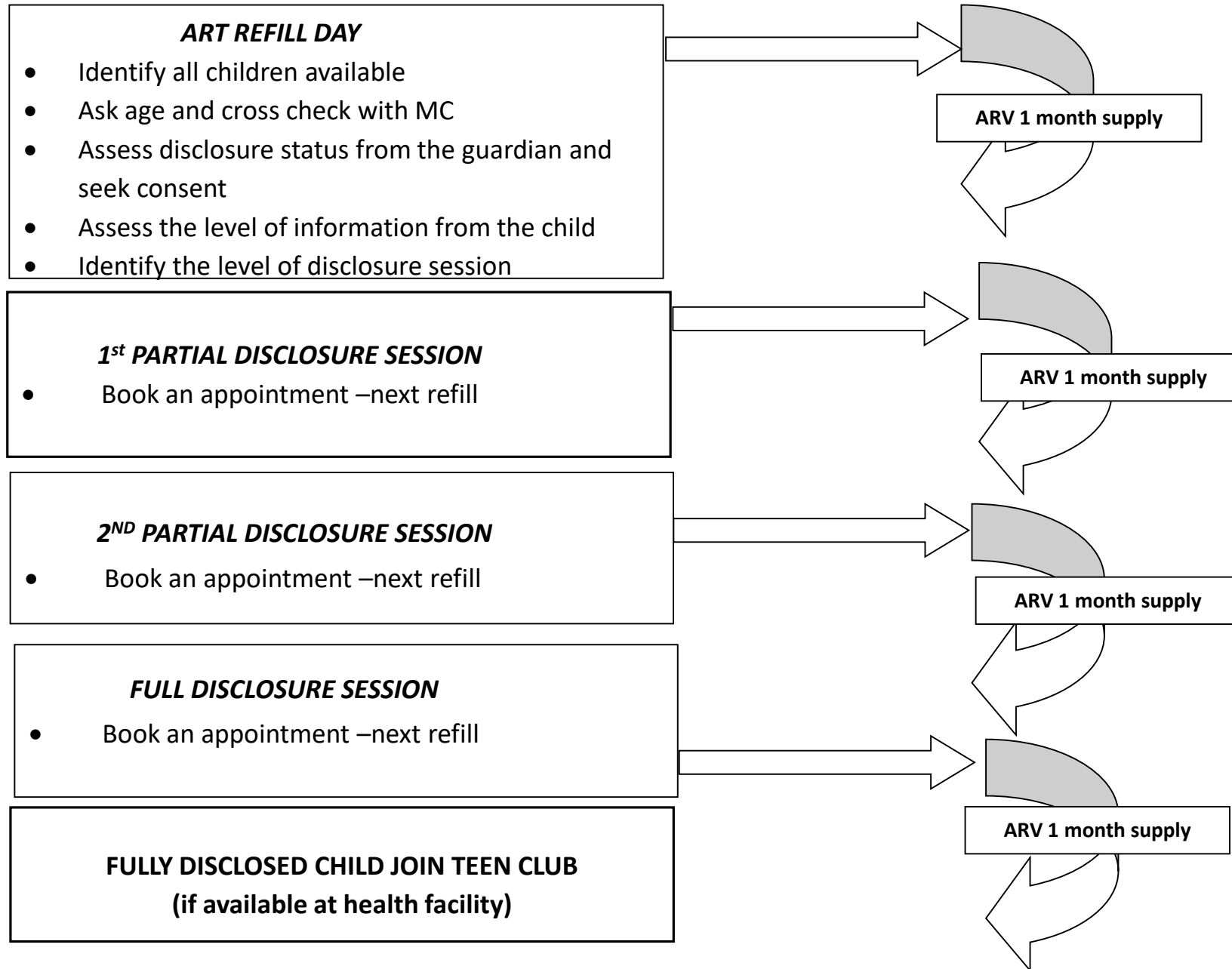
- Start as soon as possible
- Follow child's rhythm: at latest when child starts asking questions (do not lie!)
- Follow caretakers rhythm
- Verify what the child has understood
- Do not use words as HIV/AIDS in front of uninformed children

WHEN?

FULL DISCLOSURE (10 to 15 years)

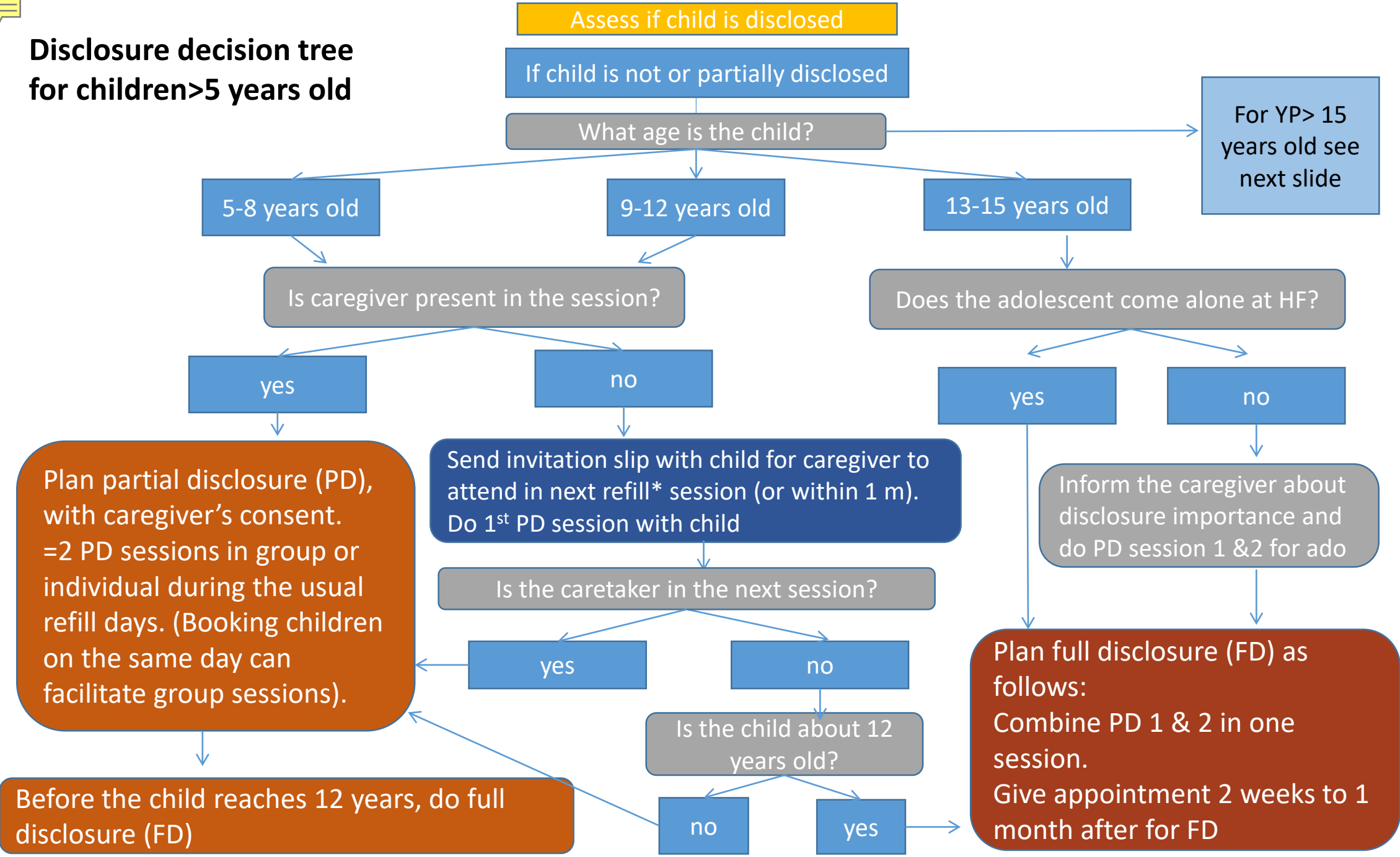
- Ideally happens between 6 and 12 years
- Do not judge or force caretakers
- When disclosure is not done at 10, we need to work with caretaker on their reluctance and advantages of progressive disclosure, so disclosure is done before 12

DISCLOSURE FLOWCHART





Disclosure decision tree for children > 5 years old



Assess if child is disclosed

If child is not or partially disclosed

What age is the child?

For YP > 15 years old see next slide

5-8 years old

9-12 years old

13-15 years old

Is caregiver present in the session?

Does the adolescent come alone at HF?

yes

no

yes

no

Plan partial disclosure (PD), with caregiver's consent. =2 PD sessions in group or individual during the usual refill days. (Booking children on the same day can facilitate group sessions).

Send invitation slip with child for caregiver to attend in next refill* session (or within 1 m). Do 1st PD session with child

Is the caretaker in the next session?

yes

no

Inform the caregiver about disclosure importance and do PD session 1 & 2 for ado

Plan full disclosure (FD) as follows: Combine PD 1 & 2 in one session. Give appointment 2 weeks to 1 month after for FD

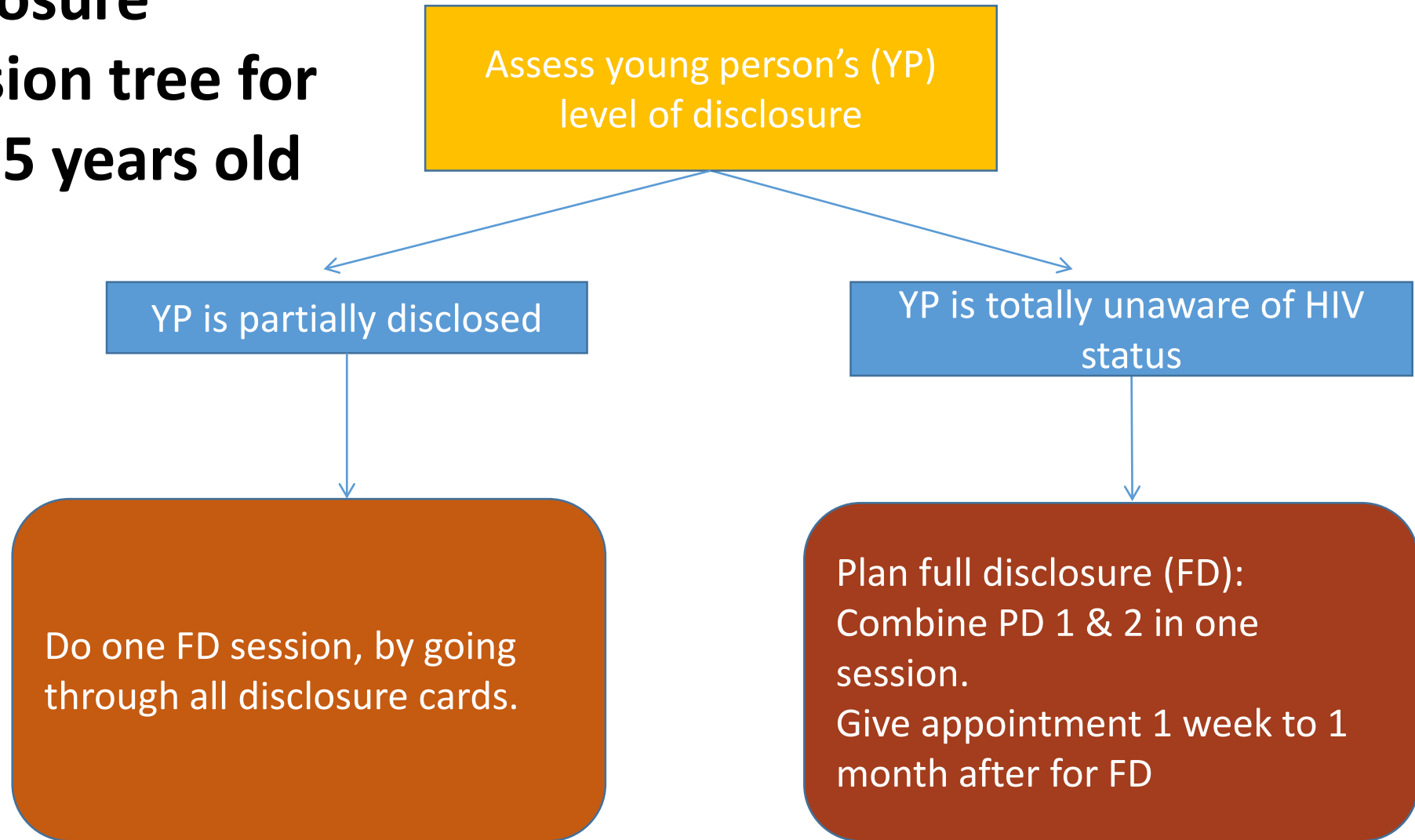
Before the child reaches 12 years, do full disclosure (FD)

Is the child about 12 years old?

no

yes

 **Disclosure
decision tree for
YP>15 years old**



DISCLOSURE PLAN

Provide information about:

- Being healthy, taking care of the body
- Visit to clinic
- The human body
- Our defenses (immune system)
- Germs and getting sick
- The immune system needing assistance from drugs
- The specific virus the child has (name the virus and the illness: HIV)
- The CD4 count and viral load
- Transmission and non-transmission of HIV, sexual relations and condoms use

DISCLOSURE SESSION 1: PARTIAL DISCLOSURE

- Card 6: My visit to the hospital
- Card 7: Human body
- (Card 5: Taking care of the body)
- Card 10: Protection by green soldiers

Use explanations about partial disclosure; do not name HIV, CD4 etc.

DISCLOSURE SESSION 2: PARTIAL DISCLOSURE

- Review card 10: Protection from green soldiers
- Card 11: Infection with red germ
- Card 14: Yellow germs entering the body
- Card 15: Taking treatment
- Card 16: Taking treatment – Inside the body
- Card 17: Effect of treatment

Use explanations about partial disclosure; do not name HIV, CD4, ARV etc.



DISCLOSURE SESSION 3: FULL DISCLOSURE

- Card (7), 8: (Human body from outside), Blood circulation (inside human body)
- Review Card 9 using full disclosure explanations: Blood and green soldiers as CD4s
- Review Card 10 using full disclosure explanations: Protection by green soldiers as CD4s
- HIV Cards 11, 12, 13, 14: Red germs as HIV
- ARV cards 15, 16, 17: drugs as ARVs
- (Cards 22, 24: Ways of transmission and non-transmission)

Name HIV, CD4s, ARVs, (explain modes of transmission)



FOLLOW UP COUNSELING POST-DISCLOSURE

- **Provide opportunities for child and family to:**
 - gather more information and understanding
 - express difficulties they are facing
- Help child to know who he/she can talk to
- **Regularly assess:**
 - child's understanding of condition
 - potential coping difficulties (e.g. behaviour change)

KEY MESSAGES

- Disclosure is a process, starting from partial disclosure to full disclosure
 - Disclosure has many benefits, including helping to improve adherence
 - Child's readiness for disclosure depends on:
 - Family wishes and available support post-disclosure
 - Age and developmental stage
 - Child's current needs and experiences
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