

# Protocol to Enhance Adherence

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## Assessing and Planning Treatment

- Consultant involved in care should discuss with the child and family the reasons why a new or different treatment regimen is required.
- A planning meeting involving all members of the MDT should be held.
- For parents and children who are not ready to start treatment, follow-up and discussion should continue where appropriate.

## A number of key issues should be considered:

- Family's readiness and motivation, understanding, who will take responsibility for giving medications, family's health beliefs and cultural issues, timings, housing and immigration status, child's and parent's previous and current experiences of anti-retroviral treatments, practicalities, child's and family's daily routines, other family members on treatments, parent's health needs, type of regimen, anticipation of potential problems, current health needs of the child, child's understanding of their diagnosis, parental preference of treatments - if possible, pre-treatment requirements, a detailed plan for follow-up.
- Outcomes of the meeting should be fed back to the parents and/or child by the consultant and CNS.
- This should detail the treatments options available and the regimen that is considered best/most appropriate for the child.
- Agreement of individual roles and responsibilities about medication giving and collecting should be identified at this point.
- Details of the follow-up plan should also be discussed and agreed.
- The start date should be agreed.
- Allowing time for questions at each stage of the feedback process is essential.
- The final decision to proceed should be collaborative.
- Information leaflets regarding each drug should be offered.
- A pre-treatment appointment should be arranged at this point.

## Starting and Monitoring - Pre-treatment Appointment

- This appointment should be carried out by the identified support worker i.e. CNS.
- At this appointment, time is available to deal with specific questions around treatments, to carry out taste tests and show the choice of treatment formulations available.
- Time should be set aside for "Pill Swallowing" sessions if required. Treatment start dates can be altered accordingly.
- Adherence aids that should be explored.
- Pre-treatment (baseline) bloods should be taken at this stage.

- Follow-up plans should be discussed again.
- Clinic appointment for week 2 should be given, together with contact numbers for out-of-hours advice should problems arise.
- Treatment can commence in clinic that day or at home.
- Where available, local community nursing team support is strongly advised.

## **Starting and Follow-up**

### **Day One**

Visit by the community team, if involved. Feedback to hospital support worker.

### **Day Two**

A follow-up telephone call by hospital support worker.

### **Week One**

If no problems identified, the community team should negotiate further visits for week 1 with individual families. Follow-up telephone calls from hospital support worker should then be at the end of week one. If problems are identified, either by community team or families themselves, then another visit by hospital and community team should be offered.

### **Week Two – Clinic Appointment**

To assess how well the family and child are coping with the medications and to explore any problems. Interventions should be implemented as soon as possible to resolve any problems. Quality of life and adherence follow-up questionnaires should be completed at this appointment.

At the week two clinic visit, the child may return charts/diaries. Positive reinforcement and a small reward may be offered at this point. A further clinic appointment for week four should be given at this visit.

### **Week Two – Week Four**

If no problems are identified weekly telephone follow-up until week four.

### **Week Four – Clinic Appointment**

The week four-clinic visit is with the consultant. To include a full physical examination and completion of adherence follow-up questionnaire / quality of life questionnaire. Week four bloods should be taken at this visit. Positive feedback and reinforcement for successful adherence should be given at all appointments.

### **Three Monthly Follow-up**

Follow-up after this point is generally 3 monthly with consultant and hospital support worker/multidisciplinary team member. At each of these visits quality of life questionnaires and adherence follow-up questionnaires should be completed. Ongoing community support may be indicated for children and families where problems re-occur. This can be offered at any point.