Promoting Adherence to
HIV Antiretroviral Therapy

AIDS INSTITUTE
NEW YORK STATE DEPARTMENT OF HEALTH
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Dear Provider,

We are pleased to present you with “Promoting Adherence to HIV Antiretroviral Therapy”, the second installment in the AIDS Institute’s series of Best Practices manuals. This unique series offers practical strategies for providers to learn about providing the best possible care to people with HIV through presentation of general principles and specific examples gleaned from the experience of HIV service providers in New York State.

This particular book represents a collaborative effort between the New York State Department of Health AIDS Institute and the New York City Title I Health and Human Services Planning Council, reflecting their support of treatment adherence programs in New York. As part of this commitment, both agencies believe that information about best practices must be communicated to a broader audience so that they can be more widely adapted throughout the range of HIV service providers. This book will be available for downloading from the Internet on our clinical website at [www.hivguidelines.org](http://www.hivguidelines.org).

You will read examples of many different approaches to providing adherence services in this book which represent creative and practical solutions to overcome a wide range of barriers. These solutions are all important, however, they are not likely to work when used alone. As you will note, a central tenet of the best practices contained within this book is that treatment adherence plans must be crafted to meet the needs of the individual patient in collaboration with her or him, in order to achieve maximal adherence to antiretroviral therapy. We believe that the success of treatment rests not only on providing specific methods, tools and incentives, but especially on how involved the patient is in developing this plan and in understanding its importance.

The web version of this manual will be updated on a regular basis. We would like to include new examples of best practices as they become known to us, and invite you to submit your examples of practices that you have developed that work to improve treatment adherence services. Please submit your examples of service delivery models or quality...
improvement efforts focusing on treatment adherence to us in consideration for posting on our website. Send these 2-3 page submissions to:

Director, HIV Guidelines Program  
Office of the Medical Director  
AIDS Institute  
5 Penn Plaza  
New York, NY 10001

Treatment adherence programs can only provide services to those people who are successfully enrolled in care and who continuously follow up with their care. These programs cannot, however, reach those individuals who have not yet interfaced with the health care system, who attend clinic sporadically or who visit multiple providers without settling into a primary care relationship. Until we can successfully reach these individuals too, we must redouble our efforts to bring HIV-infected people into care, and keep them in care so that they too can benefit from successful treatment adherence programs and improvements in their health and quality of life.

We hope that you find this book useful, and welcome your feedback. Please send suggestions to us about how we can improve this book to meet your needs. Suggestions should be addressed to the HIV Guidelines Program at the address above.

Sincerely,

Bruce D. Agins, MD, MPH  
Medical Director  
AIDS Institute
INTRODUCTION

Adherence to treatment is an essential component of HIV care. Currently available antiretroviral drugs require that patients maintain almost perfect adherence to achieve undetectable viral loads and to avoid viral resistance. In the future, HIV treatment will ideally be more “forgiving,” less complex, and easier to tolerate. Until that time, providers must be creative in devising strategies to overcome the problems that frequently interfere with adherence.

This book is designed for health care and supportive service providers who are engaged in designing or providing services to support access and adherence to combination antiretroviral therapy for HIV. Information contained in this book is intended to provide insight into barriers to adherence and practical strategies for maximizing treatment adherence.

Adherence to HIV treatment is critical to the success of improving the quality of life and survival of people with HIV/AIDS. Interventions and services should be multifaceted, tailored for each patient, and delivered through a multidisciplinary team approach that includes the patient in collaborative treatment planning. Through the New York State Department of Health AIDS Institute’s Treatment Adherence Demonstration Projects and at other treatment adherence programs across the state, best practices and creative solutions to prepare individuals for and support them through the demands of therapy have been identified.

Several sites have been profiled in this manual. These sites have demonstrated success with certain techniques and populations. Their programs are described to illustrate some of the approaches HIV health care and service programs might use to address the problems of adherence. All of the case examples provided in this booklet are based on individuals who are receiving adherence support at the profiled centers. The individuals have been given
fictitious names, and some details of the cases have been altered to protect their anonymity. By reading about the insights and perspectives of successful colleagues and the stories of program participants, providers should be encouraged to adapt these strategies as they design or refine their own adherence programs.

The book offers an overview of adherence; addresses adherence issues, including barriers, optimizing strategies (e.g., tools and services), assessment, information access, and client education; and focuses on adherence programs and their settings, multidisciplinary adherence teams, staff-client relationships, community interaction, day treatment centers, adherence concerns for special populations, and utilizing quality initiatives to improve adherence. Also included are additional readings on treatment adherence and a compilation of internet resources that offer treatment adherence information and materials. Instruments for collecting and recording adherence information used by staff at some of the identified sites are included in the appendices.
I. OVERVIEW OF ADHERENCE

What Is Adherence?

The word adherence is defined as, “the act or quality of sticking to something.” Adherence connotes the acceptance of an active role in one’s own health care. “Sticking to” the health care plan that has been developed is a crucial component of this accepted role. Ideally, the process of developing a health care plan will involve collaboration between individuals and their health care providers. Treatment plans should address the medical needs of the individual within the social context of his/her life and strategies to overcome barriers to adherence. This treatment adherence best practices manual will describe some successful ways that individuals and providers have collaborated to support efforts of people with HIV to take the medications that are so important to their health.

The term adherence is broader than the term compliance, which is used to describe the degree to which an individual follows the regimen prescribed by the provider. Adherence reflects collaboration between the patient and the provider in devising the medical regimen, not simply the following of instructions. A relationship that fosters trust and respect is essential for the care of individuals, especially for those with a chronic illness such as HIV.

Adherence: The act or quality of sticking to something; steady devotion; the act of adhering.
Adherence is best achieved through a collaborative process that facilitates acceptance and integration of a medication regimen into an individual’s daily life.

Compliance: The act of conforming, yielding or acquiescing. Compliance implies that the prescribed regimen is not a shared decision made between the individual and the provider.
Highly active antiretroviral therapy (HAART) involving the use of several medications at a time has become the standard regimen to achieve maximum viral suppression. However, these drug regimens are demanding and often “unforgiving.” The amount of time the drugs remain active in the bloodstream and their interactions with food and other drugs make timing and regularity of dosing essential to effectiveness. Missing even a few doses can lead to an increase in viral replication. Given the high frequency of mutation in HIV, this can rapidly lead to drug resistance and treatment failure. For the individual, this outcome means loss of an effective therapy to suppress the virus in his/her body. The broader public health consequence of treatment failure is the possible spread of drug-resistant virus in the community. It is important, therefore, for both the individual and the community to ensure that the necessary supports for treatment adherence are available.

One of the key principles in developing a successful treatment adherence program is cooperation and collaboration between the person taking the medications and the person prescribing the medications. True cooperation and collaboration require that each person respects the integrity and dignity of the other, even if circumstances of life and choices differ. However, patients may not respond to therapy despite optimal practices and strict adherence. This is especially true for individuals who have experience with multiple drug regimens, have problems with malabsorption, or are infected with HIV drug-resistant virus.
Who Needs Help With Adherence?
The drug regimens of HAART are very complex. Physicians and nurses cannot accurately guess whether a person will be adherent; predicted non-adherence should not be used to exclude patients from treatment with HAART. Typically, three different medications are taken in divided doses two or three times per day. Many of the medications have food requirements or restrictions, and some of the medications cannot be taken with others. Even as once-daily formulations become available, nearly all individuals will have some difficulty adhering to their prescribed schedules and will need some degree of assistance for lifelong therapy.

Everyone has needs that must be met in order to optimize his/her ability to adhere to complex drug regimens. However, there are important clues or predictors that indicate that some individuals may be more likely to have difficulty with adherence.

Predictors of poor adherence include:
- Active psychiatric illness (especially depression).
- Active drug and/or alcohol use.
- History of non-adherence.
- Medication side effects (including metabolic and morphologic side effects of HAART).
II. BARRIERS TO ADHERENCE

Barriers vary from person to person, from time to time, and from setting to setting. The treatment planning process should ensure that potential and/or actual barriers to adherence are identified and addressed. The patient and the provider can work together in a dynamic collaboration to reduce these impediments to adherence. By anticipating these barriers, programs can develop services that address the particular needs of the individuals that they serve.

**Barriers to adherence include:**

- Communication difficulties that arise when the patient’s attitude about disease and therapy is different from that of the provider’s. Without open and non-judgmental communication from the health care team, patients may not trust or may misunderstand the regimen they are prescribed.

- Unstable living situations (including limited or absent social support).

- Discomfort with disclosure of HIV status, which becomes known when medications are taken.

- Inability to set long-term goals.

- Inadequate knowledge about disease and effectiveness of medications or healthy living, including a patient’s lack of belief in his/her ability to take medications regularly.

- Difficulty accessing adequate health care.

- Housing, food, lack of childcare, or other immediate life needs, which are viewed as more pressing than taking the medications regularly.
Language Barriers

Many people with HIV use a language other than English as their primary language. It is important to have providers available who speak the same language as the patient. If this is not possible, adequate translation services should be provided. Use of community or family members as interpreters should be avoided. Although this option may be appealing, especially when the patient brings a family member to appointments, the patient may not be comfortable sharing personal information in front of another family member. Family interpreters may also alter translations by incorporating their own perceptions of what the provider and the patient say and mean. Also, using family interpreters, especially the patient’s children, places an unfair burden on those family members. Professional, trained interpreters should be used whenever possible, even though this may be difficult, especially when individuals speak an uncommon language. Sometimes, telephone translation services can be helpful.

The following are strategies specific to language barriers which may facilitate adherence:

- **Signs in languages other than English** (e.g., “Informacion”) can help to make patients feel welcome. From such signs, individuals may more easily identify the site as a comfortable place where staff members speak their language.

- **Multilingual staff should be hired**, especially if a significant proportion of the service population does not speak English well. Even if a patient speaks English as a second language, the provider should ensure that he/she is fully comfortable discussing his/her health care in English and should allow the person to request translation services.

- **Sign language interpretation** should be available for deaf and hard-of-hearing patients.

- **Large print materials or disk readers** should be provided
for the blind or visually impaired.

- **Written materials** should be available in as many languages and reading levels as applicable. Resources for materials include community-based organizations that target specific populations, as well as Internet resources, such as the AETC National Resource Center and the Centers for Disease Control and Prevention National Prevention Information Network (see Internet Resources).

- **Translated educational materials** which should be reviewed by providers or other community-based professionals who speak the language of the document. Literal translations into an English text may not be clear for a provider’s or a program’s clientele because of local or cultural variations and may create ill feelings or confusion.

**Literacy Barriers**

Low literacy levels also pose barriers to adherence. Some of the strategies for addressing literacy issues include:

- **Reviewing written materials with each patient** and describing technical terms that may be used so that the patient does not find him/herself in an uncomfortable situation where literacy deficits have to be revealed.

- **Assessing reading levels of individuals** so that providers are better prepared to tailor information to them. Written materials limited to three or four topics should be used to educate individuals with low reading levels.

- **Providing patients with pictorial** (e.g., comic books or videos) or verbal information, and with models or diagrams to supplement written materials. Pictorial information should be available free of charge in convenient locations (e.g., waiting rooms, exam rooms, and staff offices). Displaying materials in both private and public areas creates a safe space for a person to view the materials and may prompt a person to speak with a clinician about the issues raised in the printed material.
Using medication stickers which should represent the exact number of pills a person is taking and should correspond to the appropriate dose. Stickers should also include clues for when the medication is to be taken (e.g., symbol for morning for A.M. dose and symbol for food when medication is required to be taken with food).

**Barriers Associated With the Medication Regimen:**
- Frequency of dosing.
- Number of pills.
- Food requirements/restrictions.
- Frequency and severity of side effects.
- Complexity of regimen.
- Medication access/storage.

**Barriers Associated With Medication Side Effects:**
Many of the medications used in HAART regimens can have adverse health consequences. Individuals, especially those who are asymptomatic or only mildly symptomatic from HIV and who are experiencing adverse effects from their medications, may be likely to skip doses. Diarrhea, nausea, headaches, peripheral neuropathies, and other adverse effects may make a person disinclined to adhere to his/her regimen.

Proactive side effect management includes:

- **Discussing possible side effects** (e.g., potential drug and food interactions) prior to a person beginning a particular medication.

- **Concentrating efforts to plan for and to manage side effects** at times when a new drug or regimen is being started and thus medication side effects are most likely to occur.
- Giving prompt attention to medication problems. Phone access to the medical team in addition to walk-in clinic hours can facilitate prompt assessment of severity of problems and timely remedies.

- Initiating a discussion regarding an individual's side effects can assist those who may be hesitant to address such issues, especially when the subjects are perceived as embarrassing or socially unacceptable.

- Referring to peer educators and/or group meetings as good sources for individuals to share practical management tips.

Proper management of side effects is essential to adherence. Long-term drug therapy is difficult, and even minor side effects can develop into major hurdles to medication adherence.
III. INITIATION OF THERAPY

<table>
<thead>
<tr>
<th>Prescriber Checklist after Initiation of Therapy</th>
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<tr>
<td>▶ Have I determined, in collaboration with the patient, that he/she is ready to start HAART?</td>
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<tr>
<td>▶ Have I prescribed the simplest regimen?</td>
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<tr>
<td>▶ Is the dosing schedule compatible with the patient’s life-style?</td>
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<tr>
<td>▶ Have I reviewed with the patient any special instructions for taking or storing the medication?</td>
</tr>
<tr>
<td>▶ Have I reviewed potential or common side effects and considered preemptive treatment of predictable adverse effects?</td>
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<tr>
<td>▶ Did I have the patient repeat dosing times and instructions?</td>
</tr>
<tr>
<td>▶ Does the patient know how to contact the health care team for problems or questions?</td>
</tr>
<tr>
<td>▶ Does the patient know whom to and when to call for refills?</td>
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Treatment Readiness

Setting the groundwork for adherence begins even before the initiation of therapy. A consistent approach to treatment readiness helps integrate adherence as part of a patient’s routine care. Learning as much as possible about the patient’s health history, beliefs, and attitudes about HIV, treatment, and sources of social support in addition to addressing the concrete problems of inadequate housing, lack of medical insurance, domestic violence, alcohol and drug use, mental illness, or other pressing issues may be the first priorities in preparing a person for the rigors of HAART. Discussing these elements with the patient can lead to identification of potential barriers to treatment adherence (see Appendix II: Guideline for the Initial Client Visit).
Prior to the initiation of therapy, the provider may offer a “test” regimen to the patient using jellybeans or vitamins. Following this “trial run” the provider can explore with the individual any barriers or issues that arose. The “trial run” could even be extended so that the identified barriers could be addressed until both the patient and the provider feel confident in the decision to initiate HAART.

Provider Steps to Treatment Readiness

Begin adherence assessment and counseling early in HIV care.

Determine barriers to accepting therapy.

Provide adequate education about the nature of adherence, as well as HIV and therapy.

Involve the patient in the development of a treatment regimen.

Address co-existing morbidities (e.g., diabetes, hepatitis C virus) before initiating therapy when possible.

Adherence Counselor Checklist after Treatment Readiness

- Have I identified any adherence barriers and made a plan on how to overcome them in collaboration with the client?
- Have I linked the client to identified concrete and/or other social services?
- Have I reviewed with the client his/her daily routine and dosing schedule?
- Have I provided adherence education?
- Have I provided the client with tools to help with taking medication?
- Did I have the client repeat dosing times and instructions?
- Did I provide the client with written and/or visual instructions?
- Does the client know how to contact me with questions or problems?
- Has a follow-up appointment been scheduled, and does the client know when it is?
**Initiating HAART**

The issue of adherence as a component of living with HIV infection should be addressed as part of the initial patient/provider discussions about HIV and its treatment. Whenever possible, the provider should tailor the drug regimen to fit a person’s lifestyle rather than attempt to change a person’s lifestyle to fit the drug regimen. Before deciding whether to begin HAART, each individual should be fully informed about HIV and the recommended medications, including their side effects and interactions with food and other drugs, as well as about the issues of adherence.

**Rosa’s Story (Part I)**—Rosa was diagnosed as being HIV infected 15 years ago when she was in her twenties. She had struggled with domestic violence and substance use for a long period of time. She lives with a male partner who is also HIV infected. In addition to HIV, she has diabetes, hypertension, and hepatitis C infection. Rosa is the sole caregiver for her elderly, ill mother. Prior to coming to the adherence program, Rosa had been on several different HAART regimens and experienced great difficulty with adherence.

Six months after starting a new medication regimen, Rosa came to the treatment adherence program. She met for two sessions with an adherence counselor. The counselor discussed the importance of adherence and medical follow-up with Rosa. The counselor also provided education on the virus’ life cycle and how the virus might interact with her body. Rosa and the counselor agreed on use of a Medication Event Monitoring System (MEMS) cap as a support tool. By discussing Rosa’s schedule and preferences, the counselor was able to determine that noon and midnight would be appropriate times for her twice-daily doses, and the cap was programmed accordingly.
Individuals who understand the proposed treatment and participate in decisions about their care can feel that they have taken some control over their infection. By participating in the process of devising a treatment plan, a person is more likely to be able to adhere to it (see Appendix I: Treatment Adherence Plan of Care template).

Once HAART has been initiated, individuals’ adherence should be assessed at every follow-up visit or encounter to determine if there are barriers impacting a person’s level of adherence. Frequent discussions about follow-up and support can lead to identifying, preventing, and ameliorating problems that may arise between visits.

Other strategies that may help in successful treatment initiation include:

- Involving the case manager prior to the onset of therapy.
- Addressing the complex issues of co-existing medical and psychiatric illness and referring individuals for appropriate care prior to beginning HAART.
- Developing a contract or adherence plan between the patient and the provider.
- Asking the person to repeat instructions for taking medication.
- Providing written or pictorial information about the medications.
- Providing either one-on-one or group education sessions about health and prevention of illness.
- Involving or enhancing an individual’s social support network. Social support can be provided by family members, friends, peers, or program site staff members.
Focus On Therapy Initiation: Montefiore Medical Center

Montefiore Medical Center is located in the Bronx. Its adherence program is designed to provide intensive services for individuals before initiation and during the early stages of treatment. Patients receive their medical care from the hospital’s Infectious Disease Clinic.

Before initiation of therapy, the patient meets one-on-one with a member of the adherence team. Collaboratively, they develop a regimen tailored to meet the patient’s needs, put together a treatment plan that fits into the patient’s lifestyle, and address issues that could impede adherence. Whenever possible, regimens are planned in which dose taking can coincide with a person’s daily meal schedule to avoid food-drug interactions.

Following initiation of therapy, the adherence program features an 8-week intensive intervention period. Flexibility is key to ensuring that the needs of each person are met. During the intensive phase, patients meet frequently with adherence staff for counseling, which can be offered at a variety of locations: the clinic, a community-based organization, or at the patient’s home. Patients are given adherence tools, generally four different tools per patient, and shown how to use the tools. For example, a patient may have a pillbox, a reminder alarm, a pill chart, and a “buddy” who helps to maintain contact between clinic visits, provide support, remind the patient of clinic appointments, and furnish basic adherence education.

The adherence program has a close relationship with the pharmacy. Pharmacists provide individuals with medication
counseling. Medications can be delivered to a variety of locations, including to the patient’s home or to a community-based organization. The pharmacy also provides refill reminders and notifies the adherence program when an individual misses picking up his/her refills.

After completing the intensive period, the patient enters into the maintenance period. Scheduled visits are reduced to a quarterly basis. Individuals are encouraged to visit between appointments for any support or education they need. The same support services that are available during the initial phase are available during the maintenance period, and individuals are encouraged to access them as needed.
IV. STRATEGIES: TOOLS AND SERVICES FOR ADHERENCE

Adherence tools are helpful for many individuals. These can include pillboxes, alarms, or reminder systems, such as phone calls or organizers. Providers should make these devices available to individuals and should work with them to incorporate these tools into an adherence support regimen. The following list includes tools currently in use:

- **Pillboxes** are containers for storing medication with dividers for each day and each dose within the day. Some pharmacies will distribute pillboxes “pre-loaded” with the appropriate medications. Some pillboxes have removable compartments for a 1-day supply of medications that can be discreetly packed into a pocket or purse to maintain confidentiality and can reduce the inconvenience of carrying a large pillbox. Pillboxes with electronic reminder alarms are available.

- **Electronic Devices** can range from beepers to alarms to watches. Although these devices are useful, they all have limitations. Pagers that coordinate with the Internet to provide automatic text messages at dosing times are available. Providers and patients have found that alarms and pagers with text messaging capacity are more successful than simple beepers. Electronic devices should be discreet to help the patient feel that his/her confidentiality is not at risk.

- **Telephone Reminders** on a regular or intermittent schedule can help with adherence. Such reminders can be labor-intensive for the staff and, of course, require that the
person be accessible by telephone. It is important that the staff ensure that the patient is comfortable with the frequency of calls. Calling too often may be perceived as intrusive and may reduce the patient’s sense of control over his/her life. Staff must also take care to ensure that confidentiality is preserved. Scheduling calls with the assistance of the patient can help make telephone reminders a successful adherence tool.

- **Home Visits** by adherence staff or other providers, such as a COBRA case manager, can provide valuable information about life circumstances and environmental barriers to adherence. Such visits can also provide the encouragement necessary to help individuals maintain their regimens. However, home visits can be time-consuming for staff and may paradoxically encourage the patient to rely on home visits rather than to make the trip to the clinic.

- **Incentives** such as money, telephone cards, movie passes, transportation and food vouchers, as well as other small items (e.g., water bottles or notebooks) have been found to be effective with some individuals when provided as part of the treatment plan. Transportation or transportation reimbursement to and from the clinic is useful for cases in which travel is a problem and can facilitate adherence to appointments. Creatively linking the incentive to treatment can increase its effectiveness. For example, providing a water bottle to a patient on indinavir will help reinforce medication-taking and the importance of adequate fluid intake.

- **Pill Charts** visually display pills and include the name and dosage of each medication. Pill charts can be especially helpful for individuals who have literacy problems.
Organizers are calendars that help individuals develop good medication-taking habits as well as organize appointments and other commitments. Organizers can help prevent missed appointments.

Personalized Educational Materials can be developed in written, audio, or visual formats and can be tailored to meet each patient’s adherence needs. Personalized written materials can be generated with the aid of a computer. A digital camera can be used to make images of the number of pills required for daily doses taken by an individual at different times of the day.

Confidential Reminder Services, usually Internet-based companies, send messages to a person’s cell phone, pager, or e-mail account. These messages help remind the patient when to take doses and can include instructions for taking the pills and reminders for clinic and other service appointments.

A “Buddy” helps support the person in adhering to his/her regimen by providing emotional support and helping the person remember when to take the medication. The “buddy” can be a friend or family member who assists the person with adherence. He/she may or may not be HIV infected.

Medication Diaries are journals in which the patient records when he/she takes or skips doses or experiences side effects. Keeping such journal records can assist patient and provider in identifying patterns and uncovering reasons for missing doses of medication. Medication diaries provide a source for measuring missed doses.

Directly Observed Therapy (DOT) is an intensive program in which individuals take one or more of their daily doses under the supervision of adherence staff. This program may be helpful for individuals with severe challenges to adherence. Staff can prepare individuals for the weekend and holidays when it is not possible to have
DOT by observing the individual measuring doses prior to such occasions. DOT can take place in a variety of settings, including a clinic, a community-based organization, a substance abuse treatment program, or a person’s home. Individuals may be referred to the DOT program at any time during the course of their participation in an adherence program. Patients may choose a DOT program if they have had adherence difficulties in the past or have intense barriers to adherence. Some DOT programs, such as the one at Montefiore Medical Center, are designed for individuals with severe adherence difficulties. The DOT phase of the program lasts for 3 months, with scheduled visits 5 days per week at the clinic or at individuals’ homes. Each visit includes a review of a person’s medication regimen and adherence plan, observation of medication-taking, and pre-pouring of doses for evenings, weekends, and holidays.

No set of tools fits every person. The needs of each person must be assessed and discussed in a collaborative manner (see Appendix III: Adherence Assessment). The range of tools available should be explained and offered to an individual, and the specific tools used should be incorporated into a person’s routine as augmentation to other adherence measures.
Rosa’s Story (Part II)—Six weeks after Rosa’s enrollment into the adherence program, she experienced gastrointestinal distress and headache as a result of treatment. She contacted the adherence staff who relayed her concerns to the provider for prompt management. The adherence staff conducted a home visit to support Rosa through the period of distress and help her remain adherent.

Shortly thereafter, Rosa missed a scheduled appointment. The treatment adherence counselor contacted her by telephone to reschedule her appointment. Over the telephone, education and emotional support were given. When Rosa next came to the clinic, she reported taking some doses late. She described her life as being increasingly chaotic because her mother had been in the hospital. She was given a pocket beeper to remind her of dose times. At the next visit, she reported that these tools were helping her with adherence, although she felt that she was not eating well and that she was fatigued because of her busy lifestyle. She was able to consult with the nutritionist that day to address her dietary issues.

By the time of her eighth visit, Rosa’s adherence had improved substantially and her biological markers had improved accordingly. In addition to other small incentives, Rosa was issued a certificate for completing the intensive period of the program, and she moved into quarterly follow-up.
V. HOW CAN ADHERENCE BE ASSESSED?

Measuring adherence is problematic because no one method gives an accurate assessment. Some of the measures used are client self-report, electronic monitoring devices, pill counts, measurements of medications in the blood stream, and provider estimation. All have advantages and disadvantages. Since no “best” method has been identified, it is important to use multiple approaches:

- **Self-Report** - An individual’s own reports of his/her adherence (called a self-report) generally overestimate adherence. However, a self-report can correlate fairly well with actual medication-taking when a trusting relationship between the person and the provider has been established. Three-day, 1-week, 1-month, or most recent recall of missing a dose can be used to assess adherence. However, individuals may not be comfortable telling their providers that they have missed doses. Patients may tell providers what they think providers want to hear rather than what actually occurred. An environment in which a person feels safe and comfortable reporting missed doses to one or more members of the health care team should be fostered. It is useful for a provider to furnish a preamble to the self-report assessment in order to reinforce a non-judgmental attitude. An example of such a preamble is:

  “Most people with HIV have many pills to take at different times during the day. Many people find it hard to always remember to take their pills. It is important for me to understand how you are really doing with your medicine. Don’t worry about telling me if you don’t always take all your doses. I need to know what is really happening, not what you think I want to hear.”
Self-report is the most practical adherence assessment available, and its use contributes to the collaborative relationship between patients and providers (see Appendix IV: Self-Report Questionnaire).

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<td>Self-report assessment can be obtained in several different ways (i.e., interview, survey). Through questions asked in a non-judgmental manner, an individual can be given opportunities to acknowledge that he/she has missed doses. Questions can be couched in terms of number of doses taken or number of doses missed. Types of self-report questions include:</td>
</tr>
<tr>
<td>- How many doses did you take or How many doses did you miss taking yesterday? The day before that? The day before that?</td>
</tr>
<tr>
<td>- When was the last time you missed a dose of your medication? Providers, if necessary, should supply time prompts (e.g., one week ago, two weeks ago, last weekend, etc.).</td>
</tr>
<tr>
<td>- On average, how many days per week would you say that you missed at least one dose of your HIV medication?</td>
</tr>
<tr>
<td>- Which dose do you find yourself having the most difficulty taking?</td>
</tr>
</tbody>
</table>

**Electronics Devices** -
Electronic monitoring devices, such as the Medication Event Monitoring System (MEMS Cap), are useful in some settings for measuring adherence (see www.aprex.bigstep.com). The MEMS cap is a pill bottle cap with an embedded computer chip that records the date and time of each opening of the bottle. This system works well for some medications but can present problems when used in the context of HAART. Use of the MEMS system precludes the use of a pillbox, a tool that many individuals find very helpful, and is usually limited to use with only one antiretroviral drug. The MEMS cap also fails to accurately measure adherence if the
person removes more than one dose at once, leaves the cap off the bottle, loses the cap, or stores more than one kind of medication in the same bottle. In addition, these devices are expensive and cumbersome to use.

- **Pill Counts** - Pill counts can be conducted by staff members during scheduled patient appointments. Unannounced counts may be more accurate since a patient cannot predict the count and thus dump excess pills. This method is still dependent on the patient regularly bringing his/her medications to appointments. If a person is sharing his/her medications with others, pill counts can also be misleading. However, one of the biggest drawbacks to this method is that pill counts can set up an antagonistic relationship between the provider and the patient in which the provider may be viewed as the “pill police” and not an ally.

- **Pharmacy Refill Tracking** - Pharmacists can be a valuable source of information on adherence. They can provide education to individuals about their medication as well as inform the health care team about lapses in refills or problems with taking medication. Refill tracking is most useful in a closed system in which an individual uses only one pharmacist. Pharmacy records cannot stand alone as an adherence measure method because an individual may use more than one pharmacy; refills do not equate with actually taking the medication; and an individual may be receiving the medications from other sources, distributing medications to others, or simply discarding or not taking medications.
Biological Markers - Since the goal of HAART is a decrease in the amount of virus in the bloodstream (called viral load), monitoring viral load can give an indication of the effectiveness of the medications. However, some patients maintain high viral loads even though they are adherent to their medication regimen. The problem may not be that the medications are being taken improperly but rather that for these persons the medications are ineffective due to poor absorption or drug resistance. Measurement of drug levels in blood fails to take into account anything but the most recent medication doses. The techniques currently available for measuring drug plasma levels are expensive and are of limited utility as adherence measures.
### Measures of Adherence

**Self-Report** - 3-day recall is commonly used.  
*Advantages:* Inexpensive and correlates with virologic outcomes (report of non-adherence is more reliable than report of adherence).  
*Disadvantages:* Overestimates adherence. Correlation is dependent on a person’s relationship with staff. Individuals may tell providers what they perceive as socially desirable, “right” responses.

**MEMS Cap** - Embedded chip records opening of pill bottle.  
*Advantages:* Best correlation with virologic outcomes. Allows more detailed view of non-adherence patterns.  
*Disadvantages:* Expensive. Precludes use of pillbox. Fails if multiple medications are kept in a single bottle or if multiple doses are taken out at one time. Requires carrying the container.

**Pharmacy Refill Tracking** - Matching pharmacy refills with medication taking.  
*Advantages:* Timely refilling of prescriptions correlates well with adherence. Most successful when limited to person using one pharmacist. Is a useful adjunct to self-report.  
*Disadvantage:* Does not equate with medication-taking.

**Pill Counts** - Actual counting of pills.  
*Advantages:* Inexpensive and useful adjunct to self-report. Unannounced pill counts may be more accurate.  
*Disadvantages:* Tends to overestimate adherence due to pills being “dumped.” Time-consuming for staff. Casts provider in the role of medication monitor and not ally or advocate.

**Viral Load** - Monitoring of circulating plasma HIV.  
*Advantages:* Can correlate with adherence. Although poor adherence is associated with virologic failure, not all individuals with virologic failure will be poor adherers.  
*Disadvantages:* Does not necessarily indicate non-adherence. May overestimate adherence. Virologic failure can be indicative of drug resistance.

**Provider Estimation** - Of all measures, provider estimation is most poorly correlated with actual adherence.
VI. SETTING FOR ADHERENCE PROGRAM

Adherence programs have been developed in a variety of settings from storefront community-based organizations (CBO) to clinics in large hospital complexes. There is no “best” setting for an adherence program, and successful programs vary in setup. However, the following setting-related characteristics may play a role in increasing adherence:

- **Privacy** - Individuals need to be able to address their concerns in a safe, private environment. Space constraints may make privacy difficult, but candor, essential to addressing adherence, is best achieved in a private setting.

- **Location of Services** - If members of the health care team are located as closely together as possible, more time can be spent discussing treatment adherence issues. People who are already known and trusted by the patient can then introduce new services and providers in a familiar environment. Co-location of services (e.g., mental health or substance use treatment) facilitates same-day access.

- **Utilized Waiting Time** - An individual’s frustration at having to wait to be seen can be reduced by making the waiting time constructive for the individual. Creative strategies, such as on-site pharmacies and pharmacists, coordinated appointment times, supportive services in the clinic, nutritious snacks, and group support and education sessions, should be used. Many programs find that walk-in capability and 24-hour hotlines are beneficial to most individuals.

- **Informality** - Many individuals are not fully comfortable with the health care system and the authority it represents. Diminishing signs of that authority may help to increase the person’s comfort level. For example, some providers choose not to wear white coats. Other clinics have designated spaces for individuals to informally meet with each other and with providers to discuss medication taking, HIV, and other issues.
Childcare - Individuals may have difficulty finding childcare during appointment times. Providing onsite childcare or facilitating the provision of offsite childcare may make it possible for individuals to keep their appointments. If the children also are infected with HIV, childcare may be coupled with education and adherence support for the family.

Evaluation - On-going evaluation of adherence services by staff, service recipients, and the community helps define areas of needed improvement and promotes innovative solutions to space and cost limitations. Evaluation by survey, interview, forum, or advisory council can be useful. This process ensures that the program remains client-driven and responsive.
VII. A MULTIDISCIPLINARY ADHERENCE TEAM

HIV is a complex illness that has ramifications on many aspects of an individual’s health and life. An integrated, multidisciplinary approach to care can help identify issues that impact on a person’s adherence. A multidisciplinary team, which may include physicians, nurses, social workers, therapists, pharmacists, health educators, nutritionists, peer educators, and drug treatment providers, can be used to provide coordinated services for each individual.

Regular team meetings can promote good communication among the various caregivers. However, it is important that a person is comfortable with such information sharing, and the team should remain aware of the possibility that a person may be less than willing to be open with a treatment team. Issues of confidentiality in these meetings can be mitigated by letting an individual know that his/her team will discuss his/her care. These meetings serve a valuable role in coordinating care and information when individuals are aware of the actual meeting goals and do not perceive them as intrusive.

Guiding Principles for an Effective Treatment Team

- Inclusion of all disciplines involved in an individual’s treatment plan
- Establishment of regular multidisciplinary meetings to coordinate care
- Communication within team and with referral services (e.g., substance use treatment and mental health) to help identify problems early
- Information given to patients that providers will discuss individual care on a regular basis
Hospital-Based Programs
Focus on Clinic-Based Model: Bellevue Hospital Center

The adherence program at Bellevue Hospital Center follows a clinic-based model. Individuals are referred primarily from the Bellevue Infectious Disease Clinic and additionally from a community clinic and other sites. Three health educators help individuals navigate medical and social services. At all stages of therapy, individuals are brought into the program, although efforts are made to enroll people before their treatment is begun.

Initially, individuals meet with the adherence team once per week. This lasts for 3 months, at which time visits are reduced to once per month. During visits, the health educators assess a person’s adherence needs and provide education, counseling, and support. The part-time nurse on staff reviews medication regimens, observes pillbox filling, and provides information about medication. Adherence staff follow up on a monthly basis with the individual’s pharmacists, providing an additional opportunity for early intervention when an individual becomes less adherent.

A psychiatrist attends the clinic 3 days per week and is introduced to individuals in the adherence program by staff members. Two substance abuse counselors provide preventive harm-reduction counseling since substance use can negatively affect adherence. The clinic nutritionist is a valuable member of the adherence team as many individuals are able to disclose non-adherence to the nutritionist before disclosing to other team members. Case management services are provided through Bellevue Hospital, and the health educators maintain regular contact with the case managers.
“The Bellevue program functions as part of a comprehensive plan,” says Kate Berrien, Senior Health Educator at Bellevue. Individuals have a range of services available at the clinic. The different disciplines have good lines of communication and meet formally once per month to discuss shared clients. Health educators help the person to coordinate all his or her appointments, including medical, dental, and therapeutic. This provides an excellent opportunity to stress adherence as a broad concept relating to the person’s attitude toward and belief in his or her own health, which is a guiding principle at the Bellevue adherence program.

Focus on Pharmacist Involvement: Erie County Medical Center

The Erie County Medical Center’s (ECMC) adherence program is a structured educational program targeting patients who are naïve to treatment and are just starting their first HAART regimen, as well as patients who are changing their antiretroviral regimen. Individuals meet with HIV educators or a clinical pharmacist for three 1-hour, one-on-one sessions prior to starting their regimen. Sessions with an HIV educator focus on the basic understanding of HIV infection, whereas sessions with a pharmacist focus on the logistical factors associated with adherence and on proper medication administration instructions.

The pharmacist plays a key role in the ECMC adherence program. Potential adherence barriers, anticipated toxicities, pill burden, dosing intervals, and regimen preferences are discussed in detail with each person by the pharmacist on a one-on-one basis. The outcome of such a discussion is then reported to the individual’s medical provider and is used to create or revise an individualized antiretroviral regimen. The pharmacist may make
recommendations to the clinician in regard to delaying antiretroviral therapy, altering a regimen, and/or making alterations in other concurrent medications. HIV educators and pharmacists may complement educational intervention by offering individuals adherence tools, such as pillboxes, individualized dose cards, daily dosing schedules, or electronic reminders.

An individual has his/her prescription filled at a local pharmacy after the second session and is instructed to bring the medication to the third session. Therapy is actually initiated at the third educational session in order to review an individual’s understanding of the key educational concepts that relate to HIV treatment and adherence and to show the individual how a week’s worth of doses should be divided for each day among pillbox compartments. An individual is then closely monitored for his/her ability to understand, take, and tolerate the regimen and for virologic response.

As Mark Shelton, PharmD, Assistant Professor in ECMC’s Department of Pharmacy Practice and Medicine explains, “This approach has been associated with improved virologic response in treatment-naïve patients. Although this program slightly delays the initiation of antiretroviral treatment, it seems to prevent patients who are not serious about starting a new regimen from starting therapy without a working knowledge of what the regimen requires. In situations in which patients are anxious to start therapy, the timing of the educational sessions can be accelerated or combined to avoid delays in initiating therapy.”

Pharmacy services enhance the multidisciplinary team by providing the expertise of a professional who can readily address issues related to dosing and drug management. By using the pharmacist as part of the adherence team, information given to an individual is reinforced by intervention at a natural point in the process of medication-taking.
**Peer Educators As Members of the Treatment Team**

One valuable strategy for helping individuals with adherence is the inclusion of peer educators in the treatment team. Peer educators can be unparalleled role models for demonstrating the benefits of treatment adherence. They provide a unique, personal perspective in dealing with the day-to-day realities of living with HIV that health care providers often cannot. They can often forge relationships with individuals that are more candid and comfortable than those forged by physicians, nurses, or case managers. The insight and care peer educators can provide often enhance a person’s ability to understand, cope with, and ultimately adhere to a treatment plan.

The peers themselves assume great responsibilities when they join the health care team, and proper training and continuing supervision and support are essential to their effectiveness. Particular challenges associated with the use of peer workers include the peers’ own health issues and risks (e.g. substance use relapse) or the “professionalizing” of peer workers to a point at which they no longer seem to the clients to be true peers. In addition, incorporating peers into an adherence program requires that the program be otherwise adequately staffed to ensure continuity of care in the event that any peer is unable to work because of health- or adherence-related issues. Adherence programs must maintain confidentiality (10 NYCRR part 63) regarding any peer worker’s HIV status and must allow peers to be the ones responsible for disclosing their HIV status to any individual.

Peer workers not only provide one-on-one support and education but can also help co-facilitate group education and support sessions. Such services provide a good forum for individuals to share their experiences about HIV and treatment, reducing feelings of isolation. Tips on reducing adverse effects and improving adherence can also be shared in such settings. Holding these meetings in a site distant from the HIV clinic may be preferable.
The Harlem Adherence Treatment Study (HATS) is associated with the Infectious Diseases Division of the Harlem Hospital Center. Individuals in the HATS program receive their medical care from the hospital’s Infectious Disease Clinic. Many of the individuals struggle with substance use, mental health, and/or housing issues.

“The key to the program is social support on all levels,” says Amparo Hofmann, the Adherence Project Director. The main source for this support is provided from trained peer educators. All of the peers are living with HIV in the Harlem community and are interested in community service and adherent to their own antiretroviral therapies. The peers receive a stipend for their work. “The peer worker’s direct experience in dealing with HIV and treatment allows him or her to pass knowledge on to clients.”

After a client’s intake, the case manager assigns a peer worker. HATS clients are offered some participation in that assignment as they have some choice regarding peer characteristics (e.g., gender, race/ethnicity, and language). The shared backgrounds and experiences between the peers and their clients aid in the development of a trusting relationship. This relationship between the peer and client allows a broad-based concept of adherence to be developed, encouraging active involvement in care. The peer’s experiences with the medical system and HAART are invaluable resources for the client in overcoming many adherence barriers.

In addition to peer workers, HATS has a health educator who meets with participants individually and in group sessions. The group sessions are thematically organized, with the topics being generated by the participants. For example, if a person expresses interest in knowing more about the nervous system or relaxation techniques,
the health educator will organize a session around those issues. The health educator also distributes and discusses adherence tools (e.g., beepers) and targeted educational materials (e.g., fact sheets on the management of side effects of medications).

Peers receive ongoing support through supervision with a case manager which includes a review of their caseload. They also discuss any constraints that the peers may be facing as they work with individuals. Because the case managers are well versed in counseling skills, this meeting time provides the opportunity for case managers to discuss with peers issues that may additionally be impacting the peers’ own adherence or well-being. If case managers do identify peer adherence issues, then the peer is advised to see his/her infectious diseases provider and/or referred to other needed services.

Case managers, along with peer workers, are responsible for a client’s initial intake. Case managers additionally provide the link to social services for individuals. The case managers, peers, and health educators meet regularly to coordinate care for a client and to devise strategies for overcoming adherence barriers.

The Harlem program also is developing ties with several community-based organizations. In these two-way relationships, referrals for services are made in both directions. At the CBOs, the HATS program also conducts educational sessions offered through health fairs or specific talks to individuals. Not only do such services help support adherence in individuals who access them, but they also help to increase awareness of adherence services for those individuals not currently accessing adherence services through either HATS or CBOs.
Danielle’s Story - Danielle is a 30-year-old African American mother of four children. She was diagnosed with HIV infection 6 years ago when she gave birth to her son. She is a survivor of domestic violence and has been diagnosed with major depression. Her brother and several friends have all died from complications of AIDS. Danielle is highly concerned about the side effects of antiretroviral medications. She has been using cocaine to alleviate her pain and depression.

Assigned a persevering and committed peer educator who shared similar experiences and concerns, Danielle was able—after 4 months of constant resistance and denial of her HIV status—to develop a trustworthy partnership. The peer provided emotional support and motivated Danielle to participate in individual counseling sessions and support groups. Danielle shared her concerns about treatment with her peer educator, who educated her about managing side effects and the importance of adherence. Through on-going collaboration and support from Danielle’s infectious disease physician, health educator, and case manager, she has begun to address her substance use and depression. She is currently taking her medications regularly and is committed to her health care.

Gabriel’s Story - Gabriel is a 41-year-old man from South America. He was diagnosed with HIV 2 1/2 years ago when he was hospitalized with multiple opportunistic infections. Gabriel had come to the United States as an illegal immigrant. He had struggled with substance use and depression. Many of his friends have died of AIDS-related complications.
When Gabriel joined the adherence program, he was assigned a Spanish-speaking peer who had faced some of the same issues, including substance use and opportunistic infections. The two were able to form a partnership through which Gabriel was encouraged to take part in counseling and group support sessions. He was referred to a CBO that helped him obtain immigration papers. He also was able to obtain Division of AIDS Services (DAS) benefits through case management. Gabriel now sees a therapist regularly and is dealing well with his depression. Supported in this by all his different service providers, he has been able to take his medication regularly.

The Whole Team Approach

Focus On A Comprehensive Multi-Faceted Adherence Program: Joseph P. Addabbo Jr. Family Health Center

The Joseph P. Addabbo Jr. Family Health Center in Far Rockaway, New York involves the whole HIV team in its approach to providing treatment adherence services to the nearly 150 patients receiving care at the Center. Interventions are multifaceted and interdisciplinary. The doctors, case managers, and peer educators all reinforce adherence messages with clients, and weekly support groups are held that focus on client-identified adherence issues. Sometimes clinicians attend the sessions to reinforce basic knowledge about adherence. The special events and the role of the pharmacy are two features that really mark the Center’s treatment adherence program as unique.

The Center supports annual events that are promoted to people who are interested in or affected by HIV. At these events an atmosphere of informality and privacy is created. In such settings, individuals who have not yet engaged in care may talk with people
anonymously and afterward may take the initiative to make an appointment to seek care. An annual barbecue is held in a private space just behind the clinic where people can talk in a relaxed fashion and people with HIV can inspire others to take concrete steps to enroll in care. Other activities include regular bowling trips, Circle Line cruises, baseball game trips, bake sales and an HIV health fair at which the community receives information from HIV specialists; representatives from community-based agencies like the AIDS Center of Queens County can present their services; and other CBOs have opportunities to describe their prevention and support services. What makes these events so special is that the Center directly supports them through its petty cash funds, which is representative of the Center's strong commitment to providing care to the HIV community in Far Rockaway.

The Center rents space to a community pharmacy that provides comprehensive pharmacy services to Center patients. As part of these services, pharmacists provide special adherence services and work closely with the health care team to coordinate care. Among the adherence strategies used are beepers and phone calls to remind patients to refill their prescriptions or take their medications, and incentives (e.g., pizza coupons or phone cards) when patients do refill prescriptions. Pharmacists talk directly with the team when an individual misses refilling prescriptions, and similarly, case managers involve pharmacists in planning interventions by informing them of identified patient needs.

Adherence is addressed throughout the sequence of encounters during a visit to the clinic, says Michele Modeste, RN, Nurse Manager. The first contact occurs at intake when a patient sees the nurse, who determines what medications the patient is taking by asking the patient to name his/her medicines and dosages. Thus, the nurse can assess the patient’s knowledge about his/her drug regimen and verify doses. Also at intake, the
nurse asks about medication side effects to see if these exist and if they present any barriers to adherence. A case manager then sees the patient prior to the actual doctor visit, since sometimes a patient will reveal information to a case manager that he/she may not discuss with the doctor. A doctor provided with such additional information may have a more comprehensive view of actual adherence. After the patient sees and discusses treatment with the doctor, the patient before leaving again sees the case manager for review of the adherence plan.

Adherence education is incorporated into the delivery of care and includes visual aids, with stickers for pills to be taken, dosing schedule, and whether or not medications are taken with meals. Drug regimens are set up to fit with patients’ lifestyles (e.g., patients waking early or late in the day). Also, a stamp is included on each patient’s medical record to reinforce the importance of assessing and documenting adherence at each visit.

On the stamp are three questions:

1.) “When was the last time you took your medicine?”
2.) “How many doses have you missed in the last week?”
3.) “What were the reasons for missing doses?”

Answers provided to these questions are used for individualized treatment planning.

Finally, the team at Addabbo works hard to reach out to patients who stop showing up for appointments. A peer educator calls patients to find out why they have missed clinic appointments and tries to engage them to return for care. Case managers may also call or make home visits to bring people back into care.
The agency-wide commitment to supporting patients with HIV is reflected in the wide range of activities promoting adherence and also in the Center’s quality improvement program. Plan-Do-Study-Act (PDSA) cycles allow tracking of various interventions. Each member of the team enters information so that the team can assess overall the number of patients who kept visits, the number of patients receiving adherence counseling at each visit, and the number of reminder calls made. This tracking of adherence indicators helps to ensure that patients receive needed adherence services.

As Rosa Rodriquez, case manager, says, “The most important aspect of the program is getting the patient to trust the agency. Once that happens we can help people meet their needs, whether it is with getting food or with taking their pills.”
VIII. STAFF-CLIENT RELATIONSHIP

An important factor in promoting an individual’s adherence to medication regimens, especially for chronic illnesses, is the person’s relationship with his/her health care providers. He/she may have different levels of comfort with different types of providers but must feel able to trust the treatment staff, to speak openly, and to participate effectively in problem-solving. The following are some suggestions for approaching staff interactions with individuals:

- **Asking open-ended, non-accusatory questions** about medication-taking behavior promotes more open discussions of non-adherence. This approach provides an opening for the person to disclose reasons for missed doses. The person and the provider can then proceed to devise ways to improve adherence. Adversarial or confrontational attitudes about adherence are usually ineffective. If a particular health care provider is perceived as blaming a person for non-adherence, the person may stop telling that provider about adherence problems or may not return to the clinic.

- **Providing opportunities for individuals to discuss adherence** with a variety of staff members. Individuals may be more comfortable discussing adherence issues with more than one member of the team, and some individuals may tell two different providers conflicting information. This approach may help give a more accurate picture of what is really happening in each patient’s life.

- **Encouraging feedback from individuals** and modifying communication styles accordingly. This will help meet the needs of a diverse patient population.
IX. INFORMATION ACCESS AND CLIENT EDUCATION

Education is essential to promote adherence. Sources of education include:

- **Written information on HIV, HAART, and general health.** This should be available in waiting areas and distributed by providers.

- **Newsletters focusing on personal stories and which include tips for managing adverse effects and adherence.** Articles by peers are helpful to decrease feelings of isolation. Tips are especially effective when they are from patients and peer educators rather than staff.

- **Individualized education packets,** which can be generated with a computer or by combining other materials. Providing materials in a folder or organizer for an individual to take home can help provide resources for potential future concerns.

- **Videotapes available for viewing on program premises or at home.**

- **Health educators available to answer questions and provide information about both general health and HIV.**

- **Pharmacy education,** including reminders about refills which should be given when an individual is filling his/her prescriptions.

- **Group meetings** of patients, caretakers, and providers. These meetings can focus on a specific topic and can be organized as mini-lectures, question-and-answer sessions, interactive discussions, or any other effective method.
Education sessions about how to manage a visit with the physician. This assistance can improve communication between individuals and providers. Many individuals have limited experience with the health care system and may find it confusing and intimidating. Reducing these feelings can help improve communication and adherence. Education sessions can be provided on-site by staff and/or at community-based HIV organizations.

Internet access at program sites with training for staff in how to use this medium so that staff members can help individuals access material on the Internet during education sessions.

When designing education programs, it is important to take into account language and literacy characteristics of the population being served. Materials should be available in appropriate languages and at a variety of literacy levels. Pictorial materials often best meet the needs of people with low levels of literacy.
X. PREVENTING MISSED APPOINTMENTS

Missing appointments can be a serious barrier to adherence. Not only can a missed appointment be a sign of decreased motivation on the part of a person, but it can also represent a missed opportunity for a person and a provider to discuss adherence and other issues. Steps should be taken to minimize the number of appointments missed. Most importantly, a person should be made to feel that he/she is always welcome and that his/her time and presence are highly valued. Strategies for minimizing missed appointments include:

- **“One-Stop Shopping”** - A person may find it easier to make one trip to a clinic to see all the providers rather than making multiple trips. Making one trip reduces overall waiting time and decreases the complexity of appointment schedules.

- **Flexibility** - Individuals may have difficulty keeping appointments at certain times or on certain days. A wide variety of appointment times, including evenings and weekends if possible, should be made available. Drop-in capability can also increase accessibility, especially when individuals need immediate concerns addressed.

- **Reminders** - Phone calls made or notecards sent a few days before the appointment can reduce the chance of a person missing appointments. Some electronic scheduling programs can automatically generate reminder cards or phone lists. An individual’s phone numbers and addresses should be verified at each visit to make sure that they are correct and reliable. Staff must keep issues of confidentiality in mind when contacting an individual and should discuss with the individual at his/her initial visit the best way to contact him/her between visits.

- **Client Input** - The person should be asked what can be done to improve his/her appointment keeping.
Organizers - Individual organizers can be used as a reminder of appointments as well as a medication adherence tool.

Appointment Scheduling Staff - Staff involved in scheduling appointments should be trained to avoid scheduling appointments when individuals have medical, business, or care-giving obligations.

Follow-up on Missed Appointments - Determining why a person is missing appointments, especially if doing so is becoming routine, may reveal a barrier that can be resolved. There are many barriers (e.g., a person may have no transportation or may not be able to leave elderly parents home alone) for which assistance can be offered. All providers should have a system for contacting individuals to reschedule and troubleshoot after a missed appointment. Phone calls and home visits may be appropriate (see Appendix V: Home Medication Barrier Assessment).

Outreach - Developing a system of outreach for individuals may facilitate appointment-keeping. Systems can include utilizing COBRA case managers to conduct home visits, developing a buddy system among individuals, or utilizing HIV outreach workers. Frequently, escorting individuals to single or multiple appointments is helpful.
XI. COMMUNITY INTERACTION

Adherence programs should be tailored to fit the needs of the communities they serve. Social implications associated with HIV may vary within different communities. These social circumstances may alter the needs of individuals infected with HIV who are seeking treatment. Furthermore, in some communities, the array of services that are available may be limited. Individuals seeking care in any community may need help identifying and locating services. Providers should have a referral system in place to link individuals to treatment or social services that can meet identified needs.

Adherence team services can be augmented through a reduction of any stigma that might be associated with HIV and through the use of local expertise to provide services and devise programs that otherwise may not be available.

Focus On Community-Based Organizations: Brooklyn AIDS Task Force

Brooklyn AIDS Task Force (BATF) provides adherence services for individuals referred from a variety of sources, including hospital clinics and social workers. “The most important factor is the one-on-one relationship between the treatment adherence specialist and the client,” says Nadine Ranger, Research Director. This relationship allows the adherence program to function as a “safe haven” for individuals as they can comfortably discuss issues surrounding their medical care and social needs.

The treatment adherence specialists build a network of providers, including physicians, case managers, nutritionists, and others, around the patient, and this coordinated network optimizes
service for and helps promote the individual’s adherence. For example, an individual may disclose to the nutritionist that he/she is having difficulty with nausea from medications. Through that adherence specialist’s connection to the other providers in the community, the identified problem can be dealt with before it becomes a major barrier to adherence. Regular education regarding adherence helps to ensure that all providers are focused on the big picture, especially when that education emphasizes the definition that broadly defines adherence as being a part of all aspects of life.

When a person is referred to the adherence program, he/she is evaluated by the stages-of-change model; that is, the person works with the provider team to develop a treatment plan that is appropriate to his/her readiness and needs. Through this process, the person develops a sense of ownership over treatment. This may encourage greater adherence, since the treatment is the person’s, not the provider’s. An adherence specialist identifies potential barriers for adherence and refers the person to the providers of appropriate services, including case management and substance abuse counselors.

Pharmacists are brought into the adherence team, and the person is made to feel comfortable about using the pharmacist as a source of information about medications. When the person arrives to fill the initial prescription, the pharmacist provides a 40-minute counseling session and can then from that point be involved in follow-up and early identification of changing adherence patterns.

BATF also works with the criminal justice system. Individuals who are on parole or who have outstanding warrants are at risk for disruption of treatment.

For substance use and violent behavior, BATF staff provides counseling, which can prevent recurrences of activity that would
lead to incarceration. BATF counselors also work with parole officers and may even go into prisons to work with individuals.

**Geraldine’s Story** - Geraldine is a 35-year-old African American female who enrolled in a treatment adherence study. On baseline interview, Geraldine was known to be HIV infected for 8 years and had a confirmed diagnosis of AIDS. She had known risk factors for non-adherence and had experienced previous adherence problems. Geraldine had been on multiple regimens since diagnosis. She had experienced weight loss and reported difficulty swallowing because of “burning just like when [she] had esophageal candidiasis.” Geraldine stated that she had not taken any medication for a long period.

Then during a clinic visit, Geraldine expressed a desire to restart HAART. To prepare Geraldine to restart HAART, staff telephoned her and also conducted one-on-one visits. The first few days after starting her new regimen, she expressed concern about how the medications made her feel. She tried managing the side effects, but after 2 full days on medication, she discontinued the new regimen and returned very frustrated to the clinic, requesting to be switched back to her old regimen. Her provider discussed issues of treatment failure and resistance with her, and she was scheduled to return in 2 weeks to the clinic to discuss possible salvage therapy, but she failed to keep the appointment despite numerous phone conversations between her and clinic staff. Three months later Geraldine came to the clinic stating, “I realize it’s necessary to start my medication again.”
The staff again went through the process of preparing Geraldine to take HAART, and 3 weeks later, she resumed a HAART regimen. At this time her viral load was 37,616 copies/mL and her CD4 count was 19 cells/mm$^3$. At her 1-month follow-up clinical visit, she reported she had missed only 3 doses of her medication in the previous month. A CD4 and viral load were performed, and the results showed an increase in CD4 and a decrease in viral load for the first time since Geraldine had started attending the clinic.

Focus on Community Health Centers: Community Health Network

At Community Health Network (CHN) in Rochester, New York, staff physicians take the primary role of teaching individuals about the importance of adherence to HAART therapy. Nurses reinforce adherence messages during telephone triage calls, and a treatment adherence counselor (TAC) who is a health educator works with individuals to provide them with the support and skills-building techniques necessary to achieve adherence. As Dr. Bill Valenti, founding Medical Director, explains, “We use every contact with the patient to find out how he or she is doing with his or her adherence. Additionally, the multidisciplinary team meets weekly to review and modify patients’ adherence treatment plans.”

When an individual is starting or changing therapy, he/she will meet with a TAC for medication education. During this session, a dosing schedule and plan are developed based on the individual’s daily activities and eating habits. The TAC aids the individual in remembering medication dosing times through help with identification of cues linked to daily activities, provision of medication alarms, and supportive service linkages. Based on his/her assessment and the individual’s needs, the TAC provides follow-up calls and/or visits. When HAART is being initiated, TAC
visits or phone calls to individuals have proven particularly helpful in reinforcing medication-taking and providing emotional support.

The TAC makes home visits to assist individuals with changes in their medication and to reinforce adherence and will visit hospitalized individuals prior to their discharge to provide teaching about new medications or changes in dosing and scheduling. Additionally, the TAC confirms that the hospital discharge planning team has secured new medications or refills through the hospital pharmacy or the individual’s regular pharmacy. Upon an individual’s discharge, the TAC usually helps the individual set up a system organizing medications. Home visits are also provided to individuals who have difficulty attending the clinic for frequent adherence appointments or for those who feel more comfortable starting a new regimen at home.

Providing individuals with education, identifying and providing medication-taking cues, and reinforcement of strategies and emotional support have empowered those receiving care at CHN to adhere to their treatment regimen.
XII. DAY TREATMENT CENTERS: AN INTEGRATIVE, INTENSIVE APPROACH TO ADHERENCE

The day treatment model combines many recommended individual adherence approaches since this model by nature is a supportive, integrative community with co-location of an array of services. The day treatment program setting is ideal for providing the kind of education and support that is essential to optimizing adherence. Participants attend the center for several hours, several times a week, and form a bond that allows them to share in both formal and informal settings their experiences and insights into their health and treatment. Individuals also develop close relationships with other participants and the staff, enabling greater disclosure of difficulties with treatment and health. Education sessions can be focused to meet the needs of the group and can be based on topics of interest suggested by group participants. Mental health and other services can be made available at the day treatment site, facilitating participant access.

Focus on Day Treatment Programs: The Village Center for Care

The Village Center for Care (VCC) approaches adherence in a holistic fashion, addressing adherence in the context of all the social services provided to individuals. These social services are rendered in an integrated fashion through the AIDS Day Health Care Program (ADHC), a component of VCC. Individuals attend the day treatment center three times weekly for 3 hours but also are free to drop in at other times. The ADHC is open day and evening 6 days per week. An additional day for contact is provided once monthly when Sunday brunch is served.
The ADHC has an on-site pharmacy that provides medications, easing barriers to access as well as providing another opportunity for monitoring and assessing adherence. Nursing and nurse practitioner services are available at the ADHC to address immediate individual health needs and concerns.

One of the main features at The Village Center for Care is the availability of support groups. There are two Spanish-speaking groups and one English-speaking group. The groups meet weekly with a health educator leading the session. Individuals suggest topics, and the educator provides information. Individuals also have the opportunity to ask questions of the educator and of their peers and to share experiences about living with HIV and following treatment regimens.

The health educator also serves as a liaison between individuals and providers of care. Individuals are more comfortable discussing many issues with the educator, and he/she can help individuals negotiate the health care system. The health educator’s role is defined as being a resource for an individual, not a monitor of adherence. Emphasizing this role helps to ensure that individuals are comfortable disclosing their difficulties with adherence.

A psychiatrist and a psychiatric nurse practitioner provide mental health services. Program participants must see a mental health provider monthly, but most choose to access such services more often. Substance abuse counseling on-site is also available.
XIII. SPECIAL POPULATIONS

Individuals With Co-existing Conditions

A significant portion of people with HIV also have a psychiatric illness and/or use alcohol or illicit drugs. Drug users, whether active or inactive, can adhere to complex HAART regimens and should not be automatically excluded from HAART. However, the lives of some active drug users are substantially disorganized, making adherence more of a challenge. Providers prescribing antiretroviral therapy to drug users should engage them in a discussion about the level and extent of their drug use. This discussion does not mean that the provider condemns or sanctions their drug use but rather indicates that the provider is interested in hearing about their drug use in order to determine how to optimize adherence in regard to their antiretroviral medication regimen. For individuals on methadone, providers should be aware of potential interactions between certain HIV medications and methadone (For more information see Interaction Between HIV-Related Medications and Methadone at <www.hivguidelines.org>). If an individual feels that an antiretroviral medication is “eating up” his/her methadone, the provider should work in close concert with the methadone provider to raise the methadone dose or change the antiretroviral regimen.

In addition, other co-existing illnesses (e.g., diabetes, hypertension, hepatitis C) may affect adherence. Co-existing illnesses can present increased treatment requirements and side effects, drug-drug interactions, competing health priorities (e.g., diabetes may be seen by the individual as more important than their HIV treatment), and other medical problems which add layers of complexity to adherence.

Whenever possible, individuals who have mental illness and are drug users should have access to psychiatric and substance use treatment prior to initiation of HAART. Adherence programs should coordinate
services with providers of mental health and substance abuse services. This coordination should begin with the initial discussions of treatment and be integrated into the ongoing treatment plan. Regular assessment of individuals to identify emerging or recurring issues can help prevent decreases in adherence. Some specific ways for providers to improve access to services are listed below.

- **Develop relationships with substance abuse and mental health service providers** who share the aims and philosophy of the adherence program. Such providers should be included in discussions of adherence and in multidisciplinary meetings. For example, if a patient is on methadone they should be encouraged to have their methadone counselor be part of multidisciplinary meetings and involved in development of the treatment adherence plan. Substance use treatment programs can be an ideal place to provide adherence interventions, including directly observed therapy.

- **Prompt identification and referral of any person who during the course of HAART develops mental health or substance use problems** to mental health or substance abuse treatment services.

- **Follow up on referrals** to ensure that individuals are able to access the services to which they are referred. If there are problems, the provider should discuss them with the patient or with staff at the referral agency to determine if the problems can be ameliorated or if an alternative referral is needed.
Educate mental health and substance abuse service providers about adherence as they can be valuable in shaping a person’s attitudes about adherence.

Use all contacts with the health care system to encourage adherence and concern about health. Outreach efforts should be conducted to reach populations that are not accessing services. Provider visits to locations such as residential treatment facilities or methadone clinics can help form initial relationships with patients. Outreach efforts can also be extended to temporary housing sites.

Supporting individuals in addressing all their issues, medical and non-medical, will give them a better chance to lead healthy lives. (For more information, see Mental Health Care For People With HIV Infection. Albany, NY: New York State Department of Health, AIDS Institute, 2001.)

Focus On Unstable Populations: Mount Sinai Medical Center

The adherence program at the Mount Sinai Medical Center is based on the premise of building a “bottom-up system of adherence.” A three-part view of adherence is formulated, involving the client, the providers, and the overall system. Interventions at all three levels are necessary to promote adherence.

Network linkages are the backbone of the program at Mount Sinai. By making health care more accessible, many barriers to adherence are reduced. Existing points of contact between individuals and the system are utilized to promote a broad concept of adherence as a part of daily life. For example, links to substance use treatment and domestic violence programs increase the available access points for the client. Outreach efforts are targeted at locations where repeat contact with individuals is likely.
Education of service providers is a crucial component. Infectious disease physicians are targeted to increase their awareness of adherence services and concepts. Education of frontline social service workers increases the opportunities to resolve crises immediately, before they begin to seriously impact adherence.

A broad range of support groups, including groups for women, substance users, and gay men, are available for individuals through community network links. The program organizes group sessions that cover specific topics, ranging from medication side effects to general health to social issues. The development and fostering of this supportive network enables individuals to have the necessary social and psychological support to address the issues in their lives that may be impacting adherence.

**Homeless and Marginally Housed Populations**

Inadequate housing poses special adherence challenges for individuals. Since the need for shelter predominates over other needs, attention to health care and HIV treatment suffers. In addition, lack of stable housing makes storage of medications and adherence tools problematic. Without a permanent residence, individuals find it difficult to establish a fixed source of health care since they are residing in temporary domiciles at different locations. Inadequate transportation, thus, also becomes a barrier to accessing services.

Homeless and marginally housed individuals are more likely than others to be mentally ill and/or chemically addicted. Their many unmet needs hinder their abilities to become ready for treatment and should be addressed before initiation of therapy so that the success of HAART may be maximized. Some tips for those working with homeless or marginally housed individuals include:

- Establish solid lines of communication within the provider team. Case managers are especially important
team members for addressing social and medical needs which can present major hurdles to individuals in need of care.

- **Bring program services to people.** Outreach to shelters, single room occupancy (SRO) hotels, hospital emergency rooms, and other sites where homeless individuals regularly visit can help increase their access to health care systems, which is a necessary first step to adherence.

- **Educate providers of services to marginally housed populations about adherence and adherence programs** as they will be access points for initiation of contact and valuable members of the adherence team.

- **Stress adherence as a broad concept of concern about one’s health and health care at each encounter.**

**Rural Populations**

Adherence programs in small towns and rural areas present other challenges. Two prominent concerns with rural programs are the expansive geographic areas served and the particular need for anonymity and confidentiality in rural and small town environments. Personal isolation is common, especially when the person is not able to disclose his/her disease status. Many of the same adherence strategies used in urban areas are applicable to rural areas, but special efforts also need to be made to address the needs of rural populations.

Approaches that serve the needs of rural populations may also work well with urban residents and vice versa. Issues of access and confidentiality are important for all.
AIDS Community Resources (ACR) in Syracuse serves a geographically expansive community in upstate New York. Individuals are spread across 11 counties in a variety of environments, which include small towns and rural areas where people are often challenged by limited transportation, isolation, and fear of confidentiality breaches even more so than people in other settings.

Case managers play a key role in the ACR program. “Case management is an important service for the population at greatest risk for treatment failure due to poor adherence,” says Donna Valerino, the program’s Deputy Executive Director. Case managers are involved before the initiation of therapy, often at the time of delivery of positive test results. This involvement between the program and its participants allows relationships to begin early and barriers to be addressed before treatment is initiated. Since case managers see individuals more frequently than other providers, an individual’s comfort in discussing adherence issues with case managers is often increased.

Peer support is also a key component of the ARC program. Because it is not practical for each program participant to frequently attend meetings, other avenues for support have been established. One of these is a newsletter that includes personal stories from people living with HIV and allows individuals to share tips on medication adherence and managing adverse effects.
Because transportation poses a major barrier for people who live several hours from service sites, the program makes van transportation available to transport people to clinic appointments, group meetings, and pharmacies. Alternative arrangements, such as mail-in prescription refills and consolidation of appointments, can also be made for individuals.

**Michael’s Story** - Michael is a 52-year-old man. He was referred to the AIDS Community Resources adherence program after visiting the emergency room with seizures and neurosyphilis. Michael had no medical coverage and issues with unreliable housing and finances. His family who were in the area were not supportive of him or his health care needs.

Michael began accessing regular medical care while his case manager worked with him to obtain housing and income support. The treatment adherence program provided him with the social support necessary to integrate medical care into his life, and Michael now takes his medications regularly, both for HIV and for epilepsy. His CD4 count has risen dramatically, and his viral load is now undetectable.

**Tamara’s Story** - Tamara, a 38-year-old woman, sought access to the case management and adherence program at AIDS Community Resources. At the time, she was anticipating the release of her abusive husband from prison, was not engaged in medical care, and was the sole caregiver for four children.

The case manager helped Tamara to access legal services, and Tamara separated from her husband. Now her current partner, who is HIV negative, also participates in the program and provides her with support. Tamara also entered into treatment, and through the help of health educators at the program
is now able to take her medications regularly. She consistently accesses medical care, and her biological indicators have improved.

Children and Adolescents

Those who care for children and adolescents with HIV/AIDS must incorporate knowledge about developmental stages into devising and implementing adherence strategies and interventions. Typically, development can be divided into the following stages: infants, toddlers and preschoolers, school-age children, and adolescents/young adults. As a child grows older, he/she can begin to take responsibility for learning about and taking medications. This independence provides adolescents with a sense of control over their lives, which is something that chronic illness often hinders. Sexual development and peer pressure are additional developmental issues that may interfere with adherence.

Administering multiple daily doses of large pills and unpleasant-tasting liquids to children is a difficult task, made even more challenging by the stringent requirements of HAART. If the caregiver him/herself is also dealing with HIV infection, such tasks can become overwhelming. To be successful, adherence programs for children require the expertise of pediatric specialists and the collaboration of both caregivers and children. The goals of such an adherence team are to promote healthy habits and positive activities in the family and to reduce the stress of disease management.

The adherence team should include:

- The child or adolescent.
- All family members willing to participate.
- A medical provider with expertise in pediatric HIV.
- A social worker with expertise in pediatric HIV.
- Nursing professionals with expertise in pediatric HIV.
A health educator with expertise in pediatric HIV.

A pharmacy that is knowledgeable about HIV disease and treatments and that can offer support services (e.g., delivery).

Expertise in HIV pediatric management is developed through an excellent knowledge of antiretroviral treatment, pediatric growth and development stages, family dynamics, disclosure, and adherence issues. An adherence plan for a child or adolescent should consider not only the child’s medical needs and developmental stage but also the family’s resources, schedule, and level of commitment. Furthermore, the child’s ability to swallow particular medications may necessitate prescribing a certain regimen.

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<tr>
<th>Checklist for Providing Adherence Services to Children and Families</th>
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<tr>
<td>▶ A person who has primary responsibility for giving medication has been identified. A back-up person has also been identified.</td>
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<td>▶ Caregivers have expressed interest and willingness to participate in care.</td>
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<tr>
<td>▶ A medication schedule that takes into account the family's and child's obligations and routines has been established.</td>
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<tr>
<td>▶ Education about HIV and adherence has been provided to the family.</td>
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<tr>
<td>▶ Reminder systems, pharmacy services, and other support services have been set up.</td>
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<tr>
<td>▶ The family knows how to contact the health care team with problems or questions.</td>
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The first time a new medication regimen is ordered for a child or an adolescent, the provider should see that the family attends to observe the proper technique of administration and to allow the provider to observe family members administering the medication so as to help prevent errors that might cause ineffective dosing. Teaching by using the actual medications is very helpful.
To ensure that a child can take a particular medication in a pill or capsule form, the child should practice pill-swallowing using candy rather than the medication. Providers also may find it useful to set up pillboxes and actually measure liquid medications used with syringes. Adherence should be explored at each visit so that any problems may be quickly identified. By anticipating developmental changes in a child or an adolescent, the adherence team can help family prepare to change its adherence procedures and routines.

Special developmental considerations for adherence among children and adolescents include:

- **Infants** - The infant’s total dependence on a caregiver requires the adherence team to focus education and support efforts on adult caregivers in addition to the child. Helping families create realistic medication schedules is crucial. Families need to attend to an infant’s routines, including sleeping habits, level of alertness, interest in taste, and ability to move. Anticipating an infant’s developmental changes and helping families adjust medication schedules to match the families’ own schedules is vital, as a baby’s growth will affect and change its sleeping and feeding schedules. With infants, the family may find special syringes useful for administering medications.

- **Toddlers and Preschoolers** - Toddlers enjoy maintaining regular schedules and rituals. If they have been taking medications since infancy, doing so will become an accepted part of their routine. Developmentally, toddlers are testing limits and the control of those around them, testing which
may well include the toddler’s medication-taking response (e.g., a sudden refusal to take medication). As the medication will need to be given even when the toddler refuses it, discussing this potential problem with families faced with such a problem will help them remain consistent and calm. If the caregiver maintains familiar schedules and rituals and does not waver in giving the medication, the child will very quickly decide that medication is not an area where he/she can assert his/her independence. During toddler and preschooler stages, the primary caregiver will probably require some physical and emotional support, and the family should be encouraged to have at least two people who are knowledgeable about the child’s medication and available to administer it. A family caring for an unwilling child should be encouraged to ask the child’s provider to demonstrate how the family can give medication to the child safely. When a provider starts a child’s regimen with the less pleasant tasting medications, he/she should be aware that unless the family has tremendous resolve and resources such a regimen will usually not succeed. Less palatable medications can be disguised by using very sweet or strong flavors, such as mints and chocolate syrups, or a child can be offered a spoon of syrup or a strong mint just prior to and after each dose. Other initial regimen options include choosing a palatable medication combination, waiting to treat until a child is less oppositional, or offering placement of a gastric tube. The medical provider can assist the family in considering and making these choices.

- **School-Age Children** - At this stage, a child can become a more active participant in his/her own medication-taking. With adult supervision, children can learn to measure liquid medications and take such medications themselves. Children can themselves discover new foods or candies that can help hide the flavor of less palatable medications and assist with pill-swallowing. In this age group, children
often like to draw and write, and a good adherence tool can be keeping a journal about their body and their medications. For younger school-age children, positive reinforcement of good medication-taking means rewarding positive behavior. One type of positive reinforcement involves providing a calendar on which children put a sticker on the date for each time they take their medications. Children can then be encouraged to bring these calendars to provider visits and can be offered small rewards (e.g., small toys, coloring books) for full calendars.

- Older Children and Adolescents - As children grow up and develop responsibility, they can begin to take guided control over their medications. However, children struggling to be accepted by their peers and trying to avoid the social stigma of HIV infection may have a strong incentive to “feel normal” and thus not take medications. Adherence programs need age-appropriate support to help older children and adolescents continue previous and learn new healthy practices. Enlisting the help of a school nurse may be appropriate. Peer support groups have proven successful in providing safe situations for children to discuss their infection and to bond with others in similar situations. Often, families may be too willing to turn medication responsibilities over to an older child or teen, who really still needs adult support and assistance. Families need to set up supports by identifying for an older child or teen who will help him/her and when. Older children and teens often benefit from reminder systems (e.g., beepers and alarm clocks). Small, discreet pillboxes are also often appreciated. Role-playing with other older children or teens may help them plan how to solve potential problems such as how to take their medications when friends are around or what to do if they find themselves out late and do not have their medications with them.

Helping children, adolescents, and their families with medication adherence is a dynamic process, involving a team approach. When based on a child’s or an adolescent’s developmental level and a
family’s individual needs, medication adherence is most likely to succeed (see Appendix VI: Summary of the Most Commonly Encountered Pediatric Adherence Problems).

XIV. QUALITY IMPROVEMENT FOR ADHERENCE

Addressing adherence as part of a quality improvement program can help the health care team focus on goals and methods that lead to improved treatment adherence. At Montefiore Medical Center, a quality improvement process for self management and adherence support has been implemented with the goal of providing all individuals on HAART with adherence counseling or adherence intervention at the time of their last scheduled visit with their provider. Monthly, physicians and nurse practitioners in the Infectious Disease Clinic conduct chart reviews of all individuals seen that month to identify which individuals had either adherence counseling or intervention provided at their last clinic visit and to ascertain whether the provider documented all of an individual’s current medications. The information collected is maintained in a spreadsheet format that allows providers to view their cohort of patients as well as to look at aggregated data demonstrating trends over time. On a weekly basis, a quality improvement (QI) coordinator independently validates this clinical log maintained by providers. Providers meet biweekly to review and address any variance in expected quality outcomes. Patients requiring additional follow-up are identified, and strategies, such as calling patients to encourage adherence to treatment, are implemented. Expanding quality initiatives throughout the clinic is achieved
through Montefiore’s Quality Improvement Committee. The Committee, which includes representatives from all service components of the program as well as administrative and medical leadership, decides how the QI initiatives will be implemented. Quality improvement efforts and implementation of changes in practice are reviewed at weekly provider meetings, general staff meetings, and QI meetings.

Eli Camhi, Administrator for the AIDS Program at Montefiore, explains that providers often describe themselves as being “on board” with providing adherence counseling and intervention. Even routine monitoring of quality measures has been shown to stimulate provider motivation to meet and exceed standards of care.

<table>
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<tr>
<th>Steps to Initiating a Quality Adherence Project</th>
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<tr>
<td>▶ Interview providers to determine how they are currently addressing adherence and to share findings.</td>
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<td>▶ Convene a small team of providers to coordinate the adherence quality project.</td>
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<tr>
<td>▶ Develop standardized adherence measure and documentation.</td>
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<td>▶ Test on a small scale before expanding efforts to a larger group of providers.</td>
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<tr>
<td>▶ Identify where adherence messages can be incorporated into the routine delivery of care process.</td>
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<tr>
<td>▶ Routinely collect data about adherence and make the analyses available to providers.</td>
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<tr>
<td>▶ Systematically seek input from clients about their adherence needs and experiences.</td>
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<tr>
<td>▶ Assign a provider or team to assume accountability for various adherence activities.</td>
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<tr>
<td>▶ Integrate adherence monitoring and reporting into the existing quality infrastructure.</td>
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</table>
XV. CONCLUSION

Adherence is a collaborative process between an individual and his/her providers. It requires the commitment of all parties involved and is essential in the care of chronic disease, especially HIV. Individuals should be provided with the support, education, and motivation that they require to be active participants in their own health care.

Multifaceted, individually tailored adherence interventions should be integrated into the delivery of comprehensive HIV care. At each point of participant interaction, attempts should be made to reassess the efficacy of interventions, including identifying potential or actual barriers that may lead to non-adherence. Adherence programs should be designed in a manner that best reflects the needs of the community being served. Such program design may require delivery of services through peer engagement or orchestration of adherence services within either clinical or community-based organization settings. Adherence should be recognized as a complex behavioral process influenced by many factors (e.g., medication regimens, health care team relationships with individuals, individual attitudes and beliefs about medication-taking and disease). Whatever approaches a treatment program incorporates, adherence strategies will be most effective when they are considered an integral part of routine ambulatory HIV care. Through effective adherence strategies such as those highlighted throughout this book, people with HIV will have greater opportunities to achieve optimal viral suppression and desired health outcomes.
FURTHER READING


Roberts KJ. Barriers to and facilitators of HIV-positive patients’ adherence to antiretroviral treatment regimens. AIDS Patient Care STDs 2000;14:155-168.

INTERNET RESOURCES

http://www.aids-ed.org
The AIDS Education and Training Centers (AETC) National Resource Center (NRC) website has been designed to serve as a central resource for the education of providers of HIV/AIDS care nationwide. One novel feature of this website is its “Ask the Expert” question and answer forum, which provides the only widely available system by which care providers can ask questions of and provide feedback to members of the various DHHS guidelines panels.

http://www.aidsmap.com
The National AIDS Manual (NAM) in collaboration with the British HIV Association produces this site. NAM is a community-based information provider based in the UK whose sole aim is to combat the AIDS epidemic through accurate, accessible, and up-to-date information. NAM produces extensive information on treatments, both in book form and as a searchable database on its website. One of the key site features is the Personal Pill Planner, which helps individuals figure out the best time to take a particular regimen based on lifestyle patterns.
http://www.aprex.bigstep.com
Provides information about the MEMS Cap system and how to contact the company for further information. 1-888-88-APREX.

http://www.case.nyam.org
The Center for Adherence Support Evaluation at The New York Academy of Medicine. The CASE mission is to increase understanding of how best to support HIV treatment adherence. The site contains pre-formatted PubMed search strategies for HAART and adherence.

http://www.cdcnpin.org
The CDC National Prevention Information Network (NPIN) provides information about HIV/AIDS, sexually transmitted diseases (STDs), and tuberculosis (TB) to people and organizations working in prevention, health care, research, and support services. All of NPIN’s services are designed to facilitate the sharing of information about education, prevention, published materials, and research findings and news about HIV/AIDS-related, STD-related, and TB-related trends.

http://www.hapdeu.org/adherence
Washington HIV/AIDS treatment adherence demonstration project website. Provides technical information for developing treatment adherence programs.

http://www.hivguidelines.org
This website is a collaborative effort between the New York State Department of Health AIDS Institute and the Johns Hopkins University School of Medicine, Division of Infectious Diseases. Developed as a central, on-line resource that equips individuals who provide services to people with HIV infection with current, state-of-the-art tools to ensure delivery of the highest quality HIV clinical care, this site contains a section devoted to Best Practices information, including a digital version of this book.
http://www.hivforum.org
The Forum for Collaborative HIV Research is an independent public-private partnership whose mission is to facilitate discussion on emerging issues in HIV clinical research and the transfer of research results into care.

http://www.hivresistanceweb.com
HIVresistanceWeb is an independent, educational resource dedicated to the advancement of anti-HIV therapy through sharing information and expert discussion of current issues in antiretroviral drug resistance and clinical HIV virology.

http://www.lhh.org
The League for the Hard of Hearing’s website. Provides listing of services and helpful links for the hearing-impaired community.

http://www.lighthouse.org
Lighthouse International is a leading resource worldwide on vision impairment and vision rehabilitation. Through its pioneering work in vision rehabilitation services, education, research, and advocacy. Lighthouse International enables people of all ages who are blind or partially sighted to lead independent and productive lives.

http://www.medimom.com
MediMOM is a completely confidential service that uses a digital cell phone, alphanumeric paging service, PDA, or regular e-mail account to remind individuals when and how to take their medication.

http://www.medscape.com
Medscape’s products and services are designed to give healthcare professionals and consumers the healthcare information and digital data they need, regardless of where or when they need it. From traditional applications to web-based services to mobile computing devices, Medscape provides the leading digital health record and the best online healthcare information in a variety of formats.
# Appendix I

## TREATMENT ADHERENCE PLAN OF CARE

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<thead>
<tr>
<th>Date</th>
<th>Potential Barriers</th>
<th>Goal</th>
<th>Intervention</th>
<th>Frequency</th>
<th>Monitoring</th>
<th>Responsible Party/ies</th>
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<td>3. Regimen review/support</td>
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<td>4. Counseling</td>
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<td>5. Education</td>
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<td>7. Case Management</td>
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<td>9. Pharmacy Checks</td>
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<td>10. Other</td>
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<td>Adherence Tools:</td>
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<td>3. Pill Boxes</td>
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<td>4. Key Chains</td>
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<td>5. Watches</td>
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<td>6. Journals/logs</td>
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<td>8. Calendars</td>
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<td>9. MEMS caps</td>
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<td>10. Other</td>
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<td>Dates Reviewed and/or Updated</td>
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| CBO CM: | Dates Reviewed and/or Updated |
Appendix II
GUIDELINE FOR INITIAL CLIENT VISIT

› Establish Trust (on-going process) by providing: clear communication, rapport, mutual respect, assurance of confidentiality.

› Introduction of adherence program

› Identify potential barriers to adherence
  ❑ Beliefs system
  ❑ Stage of treatment readiness
  ❑ Physical health
  ❑ Emotional health
  ❑ Skills
  ❑ Prior adherence experience

› Assess current situation:
  ❑ Determine treatment category:
    ❑ Preparing to start medication
    ❑ Starting medication
    ❑ Changing treatment regimens
    ❑ Having difficulty adhering to his/her regimen
  ❑ Review treatment history:
    ❑ General health
    ❑ Substance abuse
    ❑ Mental health
    ❑ Current medications
    ❑ Known allergies
    ❑ Drug side effects
    ❑ Other treatments used
Discuss current health status:
- Overall health
- Current health & social problems
- CD4 and viral load results
- Patient goals for his/her health

Review patient living situation:
- Sleeping and eating patterns
- Work and travel schedule
- HIV confidentiality issues
- Medication storage

Establish a treatment plan:
- Describe and discuss proposed new regimen
- Document treatment plan
- Discuss potential side effects and a plan for response including prescriptions
- Give written information on drugs including names, dosing, frequency, food, and storage requirements

Support and maintenance:
- Follow-up plan, including who the client can contact with questions
- Determine how to stay in contact with the client until the next appointment
- Schedule next appointment

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Appendix III
ADHERENCE ASSESSMENT

Client ID Number: ____________

Gender: F M

County: ____________

1.) Are you presently taking any HIV Meds? ☐ Yes (Go to #2.) ☐ No (Go to #3)

2.) Complete if client has answered yes to question #1:

List the HIV medications that you are presently taking:
________________________________________________________________________
(Use back of page if you need more room.)

What do you do when you have side effects? __________________________
________________________________________________________________________

What keeps you from taking your medications on time? List reasons:
________________________________________________________________________
________________________________________________________________________

Do you need help with taking your medications on time? ☐ Yes ☐ No
What type of help? __________________________________________________________

Would you like more information about your HIV Meds? ☐ Yes ☐ No
What is the hardest thing about taking your medications? __________
________________________________________________________________________
Which statement best describes you?  (circle one)

a.) I always take my meds at the correct times.

b.) I take my meds at the correct times most of the time.  (Skip my meds or take my meds late, some of the time.)

c.) I take my meds at the correct times at least half of the time.

d.) Taking meds at the scheduled time causes a lot of problems for me so I take my meds at the correct times less than half of the time.  (Skip my meds or take my meds late, most of the time.)

Has the need for transportation ever caused you to miss a medical appointment?  ❑ Yes  ❑ No

Has the need for transportation ever stopped you from getting your medications from the pharmacy?  ❑ Yes  ❑ No

3.) Complete for everyone:

Do you know what a protease inhibitor is?  ❑ Yes  ❑ No  ❑ Not Sure

Do you know what viral load means?  ❑ Yes  ❑ No  ❑ Not Sure

Do you know what “triple combination therapy” means?  ❑ Yes  ❑ No  ❑ Not Sure

Would you like to have more information about HIV treatments?  ❑ Yes  ❑ No

Permission for use by AIDS Community Resources.
Appendix IV

SELF-REPORT QUESTIONNAIRE

Most people with HIV have many pills to take at different times during the day. Many people find it hard to always remember their pills. It is important for me to understand how you are really doing with your medicine. Don’t worry about telling me if you don’t always take all your doses. I need to know what is really happening, not what you think I want to hear.

A. How many doses did you miss:

   yesterday?______________________
   the day before that?___________
   the day before that?___________

B. When was the last time you missed a dose of your medication?

What keeps you from taking your medication?

Adapted for use from AIDS Institute Treatment Adherence Demonstration Project material.
Appendix V
HOME MEDICATION BARRIER ASSESSMENT

Patient's Name ___________________________ Completed by: __________ Date: __________

Address ____________________________________________________________

__________________________________________________________

Zip Code ________________________________

Patient's Phone Number _____________________________

Additional No. _____________________________

Instructions to get there (Train line, Bus #, Stop Name, etc.) __________

____________________________________________________________________

Does the patient need a phone-call before visit? ☐ Yes ☐ No

Building access ☐ Buzzer ☐ Security ☐ Stairs ☐ Elevator ☐ Other

Explain __________________________________________________________

Is there a pay phone near by? ☐ Yes ☐ No Where? _________________

☐ Housing Project ☐ Shelter ☐ SRO ☐ Other (specify) __________

How many people live in the home?_______ How many rooms?_______

How many of them are children? _______________________________

Conditions of the rooms ____________________________________________

Are meds stored in a safe place? (protected from the reach of children)
☐ Yes ☐ No

Rent information: ☐ Rent ☐ Own ☐ Section 8 ☐ Shelter ☐ Friends/Family

Utility services available: ☐ Water ☐ Electricity ☐ Gas ☐ Heat
☐ Refrigerator ☐ Stove ☐ Bathroom
Medication Inventory:

<table>
<thead>
<tr>
<th>Med. Name</th>
<th>Amount stored</th>
<th>Dosage</th>
<th>Exp. Date</th>
<th>Note</th>
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Is there a private space for the patient?  □ Yes  □ No

HIV awareness with family?  □ Yes  □ No

Adherence tools used:  □ Watch  □ Beeper/Alarms  □ MEMS Caps.  □ Pillbox  □ Other (specify)

Notes: ________________________________

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### Appendix VI
**SUMMARY OF THE MOST COMMONLY ENCOUNTERED PEDIATRIC ADHERENCE PROBLEMS**

<table>
<thead>
<tr>
<th>Problems</th>
<th>Intervention(s)</th>
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<tbody>
<tr>
<td>A parental report of the child not taking his/her medications</td>
<td>➢ Obtain a detailed history aimed at identification of the specific causes of his/her broad complaint.</td>
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<td>➢ Conduct an interview incorporating the “what, who, when, why, where, and how” interviewing approach.</td>
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<td>➢ Make available information in the primary caretaker’s language.</td>
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<tr>
<td>A parental report of the child disliking the taste of and refusing to</td>
<td>➢ Offer the child choices when possible on how to take medications (i.e., with juice or water; in a syringe or medicine cup).</td>
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<tr>
<td>take his/her medicine</td>
<td>➢ Consult with a pharmacist to discern if alternate dosage forms may be made available through compounding.</td>
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<td>➢ Switch to pill formulations if possible.</td>
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<td>A parental report of the child becoming nauseous and vomiting after</td>
<td>➢ Administer medications with food if not contraindicated.</td>
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<tr>
<td>taking medications</td>
<td>➢ Administer medications with 8 ounces of liquid to help reduce gastric irritation.</td>
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<td>➢ Request assistance from the school nurse if nausea and vomiting primarily occur in the morning before school. This may only be done with</td>
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<td>the family’s permission.</td>
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<tr>
<td>A parental report of adherence in the face of deteriorating clinical and</td>
<td>➢ Obtain refill history from primary pharmacy.</td>
</tr>
<tr>
<td>immunological status in the child</td>
<td>➢ Request home delivery of medications to ensure refills are being ordered on schedule.</td>
</tr>
<tr>
<td>Parental anxiety that the antiretroviral medications will harm the child</td>
<td>➢ Utilize visiting nurse services to assist with adherence assessments.</td>
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<td>➢ Utilize directly observed antiretroviral therapy (i.e., shift nursing).</td>
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<tr>
<td>Problems</td>
<td>Intervention(s)</td>
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</table>
| A parent with cognitive/psychological limitations is the primary caregiver administering the medications | ▶ Provide in-depth counseling and education on HIV disease, the immune system, and impact of antiretroviral medications.  
▶ Explore the family’s fears regarding the treatment. Discuss these concerns in a non-judgmental manner.  
▶ Collaborate with the family when making treatment decisions. Active participation in treatment choices helps decrease anxiety facilitating self-efficacy.  
▶ Refer to a support group for HIV-infected parents to provide a forum for discussion of anxiety. Peer support often proves to be most valuable in these situations. |
| A parent becomes confused about which medications are being given due to multiple names for medications | ▶ Utilize visiting nurse services. A home health aide would also provide substantial assistance to the family.  
▶ Provide the parent and child with tools to support adherence such as pillboxes and medication alarms.  
▶ Utilize color-coded bottles with a matched color-coded calendar.  
▶ Provide parent with a written schedule of medications. This illustration should include both brand and generic names and some description of the medications.  
▶ Request for the primary pharmacy to deliver medications to the clinic at the time of the patient’s clinic visit. This will provide a forum to answer any questions and assess the family’s understanding of instructions. |