

Moving On Positively

A GUIDE FOR YOUTH, CAREGIVERS AND PROVIDERS

“Change is
the law of life.
And those
who look only
to the past or
present are
certain to miss
the future.”

~ JOHN F. KENNEDY

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T SOME POINT IN TIME, ALL YOUNG PEOPLE HAVE TO TRANSITION FROM PEDIATRIC TO ADULT HEALTHCARE.

It is part of everybody's life, but for some people, particularly young people who have been involved in the healthcare system their whole lives, that transition is really hard to make. Most young people that were born with

HIV will agree that "transition" has become a buzzword in their lives. Everybody from doctors and nurses to parents and caregivers are talking about it with a mixture of excitement and anxiety. This is because young adults who were born with HIV are unique. They are part of a small group of people who have survived 15, 20 and even more

years with HIV. Advances in medication mean that these young people have long and healthy lives ahead of them, but for years they were not expected to survive and so were never prepared for adulthood. The concept of transition, therefore, is pretty new to all of us and can make us feel pretty scared. Young people are not the only ones to find these changes difficult. Health providers and families can have a hard time as well. Many teenagers who were born with HIV have been with their doctors their entire lives, so leaving that doctor for somebody else is tough. Doctors and nurses also have a hard time letting go and many parents or caregivers become anxious and confused when thinking about how their roles are going to change once their children move into adult care.

Wha

As a young person, healthcare is not the only place where change is happening. Changes in education, housing, relationships, financial responsibility and family life are going on at the same time, and sometimes that can

make life feel really overwhelming. HIV often complicates a lot of these issues. For instance, young people that have grown up with HIV often face challenges in taking their medication and maintaining their health over the long term. Adherence can become increasingly difficult in the teenage years, and often becomes a critical point in conversations about transition. In addition, many young people with HIV struggle with disclosure. First, they have to cope with learning about their own diagnosis. Then, they have to think about how and when to disclose their HIV status to their friends, partners, teachers, and employers. As teens grow older, sex, sexuality and relationships become significant pieces of their lives and navigating those issues while also preparing for a future with HIV can be really difficult.

While youth with other chronic diseases also have to deal with similar issues, the widespread stigma that surrounds HIV adds another layer of barriers. Stigma leads

t's the Deal?

many young people to live in silence about their disease, unable to talk about it in public for fear of discrimination. Stigma causes many young people to feel isolated and alone, without access to support and resources that will help them prepare for adulthood. Even stigma in the healthcare setting can keep many youth from safely transitioning to adult care. Many young people who were born with HIV have lost one or both parents, which means they may not have as much social support as other teenagers. Transitioning in healthcare may seem simple at first, but once you take into account all of the challenges that young people with HIV face in their daily lives, it just gets complicated.

Being well prepared for the transition from pediatric to adult healthcare is crucial to ensuring that young people with HIV remain healthy and active in, and outside, their care. This will also make those other life transitions a lot easier to cope with.

Who Is This Guidebook For?

This guidebook is for young people living with HIV, their parents and caregivers, and the health professionals who work with them.

What We Did.

Currently in Massachusetts, there are 254 young people living with HIV, ages 13-24, who were infected with HIV at birth. Just over half are male and 77% are Black or Hispanic. In order to better understand how to help these young people successfully transition from pediatric to adult healthcare, we talked to the people who know the most about it—young people, their caregivers and their health providers.

First, we interviewed young people and their caregivers about how much responsibility they currently take for their or their child's healthcare and why the topic of transition is difficult. We then held two large workshops with doctors, nurses, social workers, case managers and mental health professionals working with young people living with HIV. We found out what they think are the priorities for their patients these days, and how they think we can best prepare them for healthcare transition. We held another two workshops with young people and their parents or caregivers. We specifically wanted to find out what young people with HIV are most concerned about in their lives as they grow up and what the major challenges are when thinking about transitioning to adult healthcare.

Since we asked health providers, young people and caregivers the same questions, we were able to compare their answers to one another and start conversations based on the similarities and differences. For instance, we were able to show health providers that while sometimes they understand what is going through the minds of the patients they treat, other times they are really wrong. Together, we came up with some solutions to the problems that young people with HIV have, and want to share them here with you.

"CHANGE HAS A BAD REPUTATION."





What Did We Learn?

We learned about why transition is so hard; not only for young people, but for their caregivers and providers as well. We learned that transition can seem complicated and scary, just when life is starting to feel normal. Many do not trust the adult health system.

The groups we talked to had great ideas about how to improve the transition process. For instance, improving communication between patients, providers and caregivers, and having peers help who have already transitioned or who are also going through the process.

We learned that helping young people practice calling in prescriptions and managing their own paperwork will give them more confidence before transition. Providers stressed the importance of establishing a transition coordinator, ensuring access to case management, and support with issues of adherence, disclosure and mental health. Parents and caregivers explained the need for their own support and information as they help their children transition out of pediatric care.

We learned that overall, young people are excited to grow up, take more responsibility and become successful adults. Leaving a pediatric family is really hard, but treating transition as an accomplishment, rather than a dreaded reality, will make a big difference.

What Will You Learn?

This guidebook aims to help young people living with HIV, their caregivers and their health providers start thinking about the transition from pediatric to adult healthcare. Ideas for how to start the conversation about transition and tools that you can use to help make those conversations easier are provided.

The book also contains helpful hints as to things that you can all do to start the transition process early and make the experience as smooth and positive as possible.

These suggestions are here to inspire your creativity and we hope that you will take these ideas, adapt them for your specific health care practice, and add your own to them.

How to Use This Guidebook.

While we encourage you to read this entire book, there may be some parts of it that are more interesting to you than others. Use the Table of Contents to navigate the different sections.



In some sections, we talk specifically to one group, like young people. This symbol indicates these sections.



Sections written specifically for parents/caregivers will have this symbol.



Those written for health providers can be identified by this symbol.

In other sections, we present different challenges to transition and the solutions that we came up with to make the transition process easier. Anyone reading this book can try out these solutions, and hopefully, you will try them together.

Hold Up! What is Transition?

Some of you may be asking yourselves, what exactly is healthcare transition? Yes we know the technical definition—moving from pediatric to adult healthcare—but what does it really mean for me? We asked some young people what they thought transition means, and here is what they said:

- ◆ Making your own doctor's appointments
- ◆ Talking with your doctor by yourself
(e.g. without a parent/caregiver present)
- ◆ Making your own decisions about healthcare
- ◆ Calling in prescriptions for medication
- ◆ Having your own health insurance at 18 or 19
(instead of being on your parents' insurance)
- ◆ Being responsible for keeping and organizing your paperwork and medical records
- ◆ Discussing and deciding about changes in medication
- ◆ Working with doctors who work with adult patients rather than children
- ◆ Knowing who needs to know about my HIV status, when they need to know, and how to tell them



FOR YOUTH

SOMEONE ONCE SAID, “THE ONLY THING CONSTANT IS CHANGE”. As you grow older, change becomes a normal part of life and the more practice you have, the easier it will be to deal with life’s changes. Think about it. To be good at anything—schoolwork, sports, music, art—you have to practice. Being responsible for your healthcare is no different. Growing up with HIV means that you are the true expert out of everyone involved in your care. You know best how your body feels and how these changes make you feel emotionally. This guide was designed to help you find ways to communicate with your caregivers and your health providers about these changes, and give you some simple steps that you can all take together to make the transition process as easy as possible.

One of the key things that we want you to know is that you are not alone. There are thousands of young people just like you across the U.S. and the world that are going through the same changes and wondering about the same things. This book was written from the information that we gathered during our conversations with young people who have grown up with HIV from birth. Some of them have already made the transition out of pediatric care, and so they shared their experiences and what worked best for them. Others have not made that transition yet, or are going through the process right now, so were able to share with us what they feel are the most important areas of support that they need to make the transition go smoothly.

In this guidebook, we share with you the concerns that young people in Massachusetts told us about when they think about transition, and then some of the solutions that they came up with. This is not a set of rules or even a checklist that you have to follow. Rather, it is a set of tips to help you with transition no matter where you are in the process. If you are just starting, it will provide you with things to think about and questions to ask. If you have already had some conversations about transition with your health providers and caregivers, the



FOR YOUTH

book has some useful tips on things you can do to practice so that when you move to adult care, you are well prepared. If you have already successfully transitioned to adult care, then reading this guidebook may help you with some ideas of how to keep a positive and trusting relationship with your adult care provider over the long term.

Whether or not you read through this entire guidebook right now or want to save it for when you are ready, we want you to know that you are not alone and that you can take your time with this process. Growing up and facing changes can be very scary, but it can also be a really liberating and powerful experience. We hope that some of the suggestions we have in this book will make it that way for you.

"THE ONLY THING CONSTANT IS CHANGE"



“He knows
it’s important,
I’ve been telling
him this all
his life, but he’s
a 20 year old boy
and thinks he’s
invincible.”

~ MOTHER



FOR CAREGIVERS

THE TRANSITION PERIOD CAN BE REALLY CHALLENGING for parents and caregivers who have been heavily involved with a child's healthcare for his or her entire life. Caregivers often feel very anxious about leaving a pediatric doctor behind who has known and cared for a child since birth, and who sometimes takes on the role of co-parent. Caregivers also tend to be nervous about giving up responsibility once their child moves onto adult care. You may be feeling nervous that your child cannot take on all of the responsibilities that you took care of all of these years, or that your child will stop adhering to medications and become sick. You may even start to feel a bit left out as if you are not needed anymore. If you are a parent and are also living with HIV, coping with transition on top of everything else can be especially overwhelming. All of these feelings are perfectly normal and happen to every parent or caregiver of a child with chronic illness.

In order for your child to make a positive and healthy transition into adult care, it is important that you feel prepared and positive about the experience as well. You have played an enormous part in the success of your child's health up until now, and your role is not just going to disappear. However, it is going to change and understanding what those changes are and how to cope with them will help make transition a liberating and powerful experience for you and your child, rather than a scary one.

One of the key aims of this guidebook is to let you know that you are not alone. Thousands of caregivers around the U. S. and the world have the same concerns as you do about helping their children enter the adult care environment. In talking with some of them, we learned a great deal about what parents and caregivers are most concerned about, and what would help ease their worries and smooth out the transition process. Many of those suggestions are in this guidebook. This book is not to be used as a set of rules or prescription to be followed, but rather as a set of tools to help you think about the transition process, start conversations with your child and their health providers, and start making simple changes to ensure your child's transition is successful.



FOR PROVIDERS

WHETHER YOU ARE A PEDIATRIC CARE PROVIDER AND HAVE BEEN WITH A YOUNG PERSON FOR HIS/HER ENTIRE LIFE, OR AN ADULT PROVIDER COMPLETELY NEW TO ADOLESCENT HIV CARE, THE TRANSITION PROCESS CAN BE JUST AS CONFUSING AND DAUNTING AS IT IS FOR YOUR PATIENTS. Research has shown that health providers often have as much trouble letting go of their patients as youth and caregivers do of their pediatric providers. As a provider who may have cared for a perinatally infected young person from birth, you can become a surrogate parent, within a care environment that rewards nurturing, enabling and incentivizing. You may worry that your patients will struggle to adhere to their medications, understand their lab results or manage their self-care once inside the adult system. As an adult care provider, your caseload is enormous and the majority of HIV infected patients that you see were infected in adulthood. Working with a young adult who was infected at birth, and who therefore faces a number of psychosocial and physical challenges unique to perinatal infection, can seem complicated and overwhelming.





FOR PROVIDERS

This population of young people living with HIV is especially important because they are setting a new precedent for chronic care in a patient group that was not expected to survive. Because nobody thought they would reach adulthood, discussions about adult medical care, college, planning for the future or having families were often left out of the teenagers' upbringing. Consequently, many young people are dealing with a host of psychosocial challenges that while difficult for anyone, are further complicated by HIV. These include adherence to medication, disclosure, managing relationships, establishing independence, and having sex. Young people with HIV face higher rates of depression and anxiety than their uninfected peers, with high levels of stress and often a dearth of family and social support. Most come from low-income families, facing inequities in education and healthcare. Higher rates of exposure to parental loss, community and domestic violence, and substance use mean that dealing with healthcare transition is much lower on the list of acute and pressing priorities for these youth.

Variations in cognitive experiences and family life critically affect how a child will come to understand transition. Therefore, there is no defined age at which transition planning should begin. For many patients, it can start as early as 12 or 13. For others, it is much later.

The solutions for successfully transitioning young people with chronic illnesses from pediatric to adult healthcare are complex and constantly evolving. There is no prescription for transition and successful transition will often come down to the individual needs of the patient and his/her caregivers. However, there are a number of steps that you, your patients and their caregivers can take to start thinking and talking about the transition process. Whether you are helping a young person transition out of your care or welcoming one in, this guidebook will provide you with some simple ideas for getting the conversation started, as well as things that you can do to better prepare yourself and your patients for transition.

Top Ten Reasons Why Transition is So Hard. We asked young people, their caregivers and their health providers about what the biggest challenges are to making a successful transition from pediatric to adult healthcare. Since the responses from all of the groups were so similar, this top ten list is a summary of all of their perspectives.

1. FEAR. Everybody is scared! Youth and families are scared of the new provider system. Pediatricians are scared to let go of patients and families they have known for years.

2. It's complicated! Transition is not that easy to understand and many young people don't understand what it all means. Health providers and caregivers who are going through the transition process with their patients and children for the first time may also find it very new and confusing.

3. Lost in transition. Pediatric and adult health care providers do not always communicate well with one another. On top of that, there is no set language for transition. Every institution has its own. So the protocols and policies vary, meaning patients get lost in the shuffle.

4. Youth aren't ready. Young people sometimes lack the skills and confidence to take responsibility for their care. They don't want to grow up, lose relationships or be treated differently.

5. Adult care is foreign. Often, adult care is in a different building or different institution and is confusing to navigate. Youth do not know how to get there or where to go once they arrive.

6. Sticky situation. Sticking to medication is hard and youth do not always understand the importance of adherence.

7. TMP "Too Much Parenting". Sometimes, the parent or caregiver is too involved in the young person's care which makes it very difficult to shift responsibility over to the patient. On the other hand, some caregivers are not involved enough, meaning the young person does not feel supported when taking on new responsibilities.

8. Lack of support. Young people do not have access to the support they need, including psychosocial support, support groups and social networks, to successfully transition from pediatric to adult health care.

9. Caregivers lack the support they need to cope with their children's diagnoses, their own diagnoses and with their children's adherence to medication.

10. Lack of opportunities. Once young people leave pediatric care, they are left with fewer opportunities to access job placement support, transportation assistance, peer support and leadership development programs.



THE NEXT FEW PAGES CONTAIN A BUNCH OF IDEAS THAT WE CAME UP WITH IN OUR CONVERSATIONS WITH YOUTH, PROVIDERS AND CAREGIVERS about how you can start preparing for healthcare transition. Try them out and see what you think! Feel free to change them in any way you want so that they work for you. Remember, transition does not have to be a terrible experience. It should be powerful, liberating and the natural next step as youth grow up into healthy and successful adults.

Solutions.

Start Early, Include Everyone.

Transition is not a single event. It is a continuous process, and if done successfully, spans many years and includes a large team of people. Start talking about transition early, even if it won't happen for a few years. Providers, make sure that young people and caregivers understand what the transition process is going to look like, and how each of their responsibilities will change. Think about the key pieces of information that they will need, and things they can do to start preparing early so that the changes don't seem so overwhelming when they start to take place.



FOR YOUTH

- ◆ TAKE SOME TIME TO MAKE A LIST OF ALL THE PEOPLE YOU KNOW who can help you make a successful transition to adult health care. These can be people from your health clinic, social service agency, youth group, faith community, family and friends. Ask those people to help support you through transition. You will feel better knowing that there is a circle of people around you who will help you if things get tough.
 - ✓ Parent
 - ✓ Doctor
 - ✓ Nurse
 - ✓ Social worker
 - ✓ Minister
 - ✓ Guidance counselor
 - ✓ Best friend
- ◆ PREPARE A LIST OF QUESTIONS FOR YOUR DOCTOR about transition, before your next visit. Make sure you have a pad of paper or a cell phone that you keep with you during the day and by your bedside (some of our best ideas come in the middle of the night!) so that you can easily write them down when you think of them. That way, you won't forget them when you have the chance to talk to your doctor.
- ◆ When the time comes close for you to switch to a new provider, ask your pediatrician to help you prepare a list of questions for your new doctor.
- ◆ Have someone go with you for the first few appointments (friend, peer, social worker) for support.



FOR CAREGIVERS

- ◆ **PREPARE A LIST OF QUESTIONS** for your child's health providers—both the new and the old. Keep a pad of paper with you or type them into your cell phone when you think of them, so that when you have the opportunity to see the doctors, you will be armed with questions for them.
- ◆ **REACH OUT TO PEOPLE IN YOUR SUPPORT NETWORK** and let them know that you may be going through some changes and need their support. Are you a part of a peer support group for parents and caregivers? If so, tell them that you are getting ready for your child's transition and can use any advice they have. If not, ask your child's doctor or social worker to recommend one for you.
- ◆ **LOOK INTO ANY CHANGES IN INSURANCE** for your child and be prepared to make those changes so that there are no gaps in care.
- ◆ **Do you know who your child's new adult healthcare provider will be?** If not, ask your child's pediatrician or social worker to help you find one. Think about whether your doctor would be a good choice.

“He knows a lot more than he lets on... He knows about taking care of himself and others, sexual partners... at 14, he is starting to be concerned about these things.” ~ FATHER



FOR PROVIDERS

- ◆ TAKE A FEW MINUTES TO THINK ABOUT THE SHIFT IN RESPONSIBILITIES as young people transition out of the pediatric clinic and into adult care. What information do they need to have with them and how can you help prepare them with it beforehand? Provide them with some resources or people to talk to, to help them prepare adequately. Some things to think about:
 - ◆ **Transportation to and from the clinic.** While many pediatric clinics provide travel vouchers, not all adult clinics will. Find out how your patients can get assistance with travel and make sure that someone is available to help them figure that out. A social worker or case manager would be a great resource.
 - ◆ **Changes in health insurance and coverage, particularly in accessing treatment.** Developing a resource guide on insurance coverage, co-payments, ADAP/HDAP and changes in the adult health system could be a great way to keep patients and their families informed.
 - ◆ **Finding the right provider.** Do you know where your patient will be going for adult care and who will be providing it? If not, try to find out. If you don't know yet, help put together a list of providers for your patient to look at. In our discussions with young people, they told us that the ability to choose a new provider, rather than just be referred to one, makes for a better transition experience.



FOR PROVIDERS

◆ **Creating a medical passport.** If a young person is moving onto a new doctor, all of his medical information, with lab counts and prescriptions, should be in one file that he readily understands. Simply transferring a medical record to another provider is not sufficient. Youth need to understand their own medical information and be able to communicate effectively with a new provider about their treatment and health status. What information can you give to the adult care team that isn't on the medical chart, but is equally important? Preparing a comprehensive health history of your patient will ease the anxiety that he and you feel about transitioning care to someone else.

If possible, have the young person help you prepare his health history, so that he feels informed about how you and the adult providers are communicating. A health history will also mean that youth may not have to tell their story over and over again to new providers – an experience that many describe as difficult and frustrating.

◆ **Preparing patients with questions.** One of the scariest things for a young person entering the adult care environment is not just whether she knows enough about adult care, but not even knowing what to ask. Help make this situation easier by putting together a list of questions for the new care provider with your patient so that she feels better prepared to have an adult conversation in the examining room.

◆ **Specializing care.** Remember that pediatrics is very different from adult care. In the pediatric clinic, all of the care falls under one roof. Moving onto adult care means that a young person must know about primary care, internal medicine, infectious disease, OB/GYN and other specialties. Make sure to talk about these different specialties with your patient and family, and provide them with any resources that you have about navigating the adult care system smoothly.

Shift Responsibility.

TRANSITION IS MARKED BY MAJOR CHANGES IN RESPONSIBILITY. When at one time the health provider and caregiver were responsible for all aspects of a young person's care, all of a sudden, it is left up to the young person to take care of herself. This can be scary and leave all of you feeling really unprepared.

be responsible

To help make the shift in responsibilities easier, start practicing early. There are a number of things that a young person can start doing on her own, with supervision and support from health providers and caregivers, to start taking responsibility for her care early. Youth can learn to take on new and important tasks, while at the same time, providers and caregivers can feel more comfortable about letting go.



FOR YOUTH

RESPONSIBILITY RUNDOWN Make sure you can answer all of these questions before you fully transition to adult health care.*

- ✓ What are the names of your health providers (include doctors, nurses, social workers and others involved in your care)?
- ✓ Do you have their contact information written down and with you at all times?
- ✓ Where are your health providers located?
- ✓ What do your doctors specialize in? Is one an infectious disease doctor? Another a dermatologist? Another an eye doctor, etc.?
- ✓ How do you get to your doctor's office?
- ✓ During what days and times can you make an appointment to see the doctor? How long do you normally have to wait to get an appointment? What information do you need handy to make an appointment?
- ✓ Who do you call when you are having a problem?
- ✓ What kinds of problems would make you call for an appointment? What about a same-day appointment? What about going to the emergency room?

* Adapted from "Transitions in Healthcare: A Guide for Teens with HIV/AIDS and their Families", by the AIDS Alliance for Children, Youth and Families.



FOR YOUTH

See if you can practice doing all of these things before you fully transition to adult health care.*

- ✓ Call in a prescription for medication to the pharmacy.
- ✓ Go into the pharmacy and pick up a prescription.
- ✓ Fill out medical forms.
- ✓ Book medical appointments on your own.
- ✓ Go into the examination room by yourself.
- ✓ Ask your doctor questions and tell him how you are feeling. Make sure you ask, and can answer, these three questions: “What is my main problem?” “What do I need to do?” and “Why is it important for me to do this?”*
- ✓ Honestly answer questions that the doctor asks you.
- ✓ Remember what the doctor says to do.
- ✓ Look up information on the Internet or read materials from the doctor’s office about growing up with HIV.
- ✓ Keep a notebook with information about your health, including your diagnosis, the medications you are on and phone numbers for your doctors.

* From the National Patient Safety Foundation



FOR YOUTH

It is okay to say that you do not understand something. When you talk to your doctor about your health, do not be afraid to ask questions. If your doctor says something that is confusing, stop her and ask her to explain what she is talking about in a different way. Whenever you think of a question that you have for your health provider, write it down in a notebook or in your cell phone, and take those questions to your next appointment. Make sure to ASK them or give your doctor the list of questions that you wrote down.

Remember, doctor's offices are confidential so when you are alone with your doctor, you can ask any question you want and get an honest answer. Try going into the examining room without your parent or caregiver next time you go to the doctor, if that is what you normally do. If you want to try it for just the first half of the visit, and then ask your caregiver to join you to go through any questions you may have missed, that is fine too.



FOR CAREGIVERS

- ◆ COME UP WITH A LIST OF RESPONSIBILITIES that you take on for your child's care and find ways to teach her to help you with them. This does not have to happen all at once. Perhaps the next time you call to book a medical appointment, do it on speakerphone so that your child can listen. The next time after that, let your child do the talking but stay there to help in case she needs it.
- ◆ IF YOU DO NOT ALREADY, LET YOUR CHILD GO INTO THE EXAMINING ROOM ALONE on his next visit to the pediatrician. Make sure he is prepared to ask any questions that he has, and assure him that you are right outside if he is uncomfortable. If you are still nervous, leave them alone for most of the appointment and then at the end, make sure you have some time with them to ask any remaining questions that you have.
- ◆ TALK TO YOUR CHILD ABOUT WHAT SHE NEEDS TO DO TO REMAIN HEALTHY. In addition to taking and adhering to medication, talk about eating well, exercising and getting enough sleep. If you don't know enough about these, ask your health provider or your child's health provider for information.
- ◆ SET IMPORTANT MILESTONES AND REWARDS TO CELEBRATE YOUR CHILD'S PROGRESS. The rewards do not have to be big. Even just a hug and some praise are great. Make sure to congratulate your child on his accomplishments as he practices taking more responsibility.



FOR PROVIDERS

For Adult Care Providers:

- ◆ ALLOCATE SOME EXTRA TIME for your first visit with a young person to discuss expectations and procedures of the health practice.
- ◆ DURING YOUR INITIAL VISITS WITH A PATIENT, CHECK IN to see if she feels comfortable taking on new responsibilities for her care. See if she has ever called in a prescription or appointment in the past, or whether she knows where the pharmacy is and how to get there. If she seems to be having trouble, ask if there is a social worker or case manager that works with her that you can talk to about supporting her through these changes.

For All Care Providers:

- ◆ DEVELOP A CURRICULUM AND TRAINING PROGRAM for families and youth that addresses different health topics related to transition. Workshops could address these shifts in responsibility and give young people the opportunity to practice. Role-play is a great tool. Topics may include managing medication, calling in prescriptions, how to interpret lab reports and manage negative side effects from medication. Other essential topics include disclosure, sexual and reproductive health, healthy living, nutrition, exercise and dental care.
- ◆ PARENTS/CAREGIVERS AND YOUTH CAN BENEFIT FROM WORKSHOPS about the healthcare system, types of providers, insurance, entitlements, how to manage co-payments and other resources.

introductions

Get to Know Each Other.

PEDIATRIC AND ADULT CARE PROVIDERS ARE NOT USUALLY IN THE SAME BUILDING and are often divided between inpatient and outpatient settings. Once an adult care provider is identified, set up some time for everybody to meet and talk about the young person's care. This gives pediatric providers the chance to educate the adult care providers about the patient's specific needs, and gives the adult care provider a chance to talk with the patient and their caregiver about what the adult care experience will be like.



FOR PROVIDERS

For Adult Care Providers:

- ◆ **INVITE YOUR NEW PATIENT AND CAREGIVER ON A TOUR** of the adult health care clinic where they will be going for care. Many of the youth and their caregivers told us that figuring out where to go and getting a tour would greatly relieve the anxiety they feel about moving to a new facility.
- ◆ **TAKE SOME TIME TO LEARN ABOUT ADOLESCENT HIV.** Even if you treat adults living with HIV, understand that youth who have grown up with the disease have unique and pressing needs. Take some time to learn about these so that you feel prepared to answer any questions that the patient may have. There is also a growing body of literature on healthcare transition for perinatally infected youth with HIV. Make sure to check it out.
- ◆ **PREPARE YOUR PREDECESSOR.** Before transitioning to you, your patient was with a pediatrician, possibly for her entire life. The pediatrician wants to make sure that his patient feels adequately prepared to transition to adult care. You can help in this process by communicating with the pediatrician about what the patient should expect and what information she should come with. Reach out and share your knowledge.
- ◆ **STAY IN THE LOOP.** Create a “communication loop” between all of the people in the young person’s support system, on the pediatric and the adult sides. The youth that we spoke with who have successfully transitioned, and who feel confident about their care, felt they had a “supportive team” of adults that they could talk to. They do not want to feel that they are left on their own and have to solve problems without any guidance.



FOR PROVIDERS

Hold a Transition Day

Once or twice a year, hold a transition day at your medical institution where pediatric and adult care providers, patients, families and anyone else involved in the young person's social support network can meet one another and talk about the transition process. This would be a great place to bring young adults with HIV to talk about their experiences and share what they learned along the way.



“I liked how they
(my pediatric
care team) asked
me if I felt
comfortable and
if I had anyone
in mind... I felt
like I had my own
opinion on it.”

~ AGE 18

Build on Past Success.

THE TEENAGE YEARS ARE FILLED WITH TRANSITIONS, some of which come easy to us and some of which are more difficult to manage. These often include changes in our social groups, moving among different groups of friends, gaining new ones and losing others. Relationships, both peer and romantic, become a bigger part of our lives. We may transition through many relationships during this time, or even explore different aspects of our sexuality. In school, lots of changes are going on. We may be starting to think about options after high school such as college or job training programs. Many of us begin working during our teenage years as well as find new hobbies and interests. It's important to recognize what helps you get through these transitions and use what you have learned to help you with transition in care.

experience



FOR YOUTH

For Youth (and Caregivers)

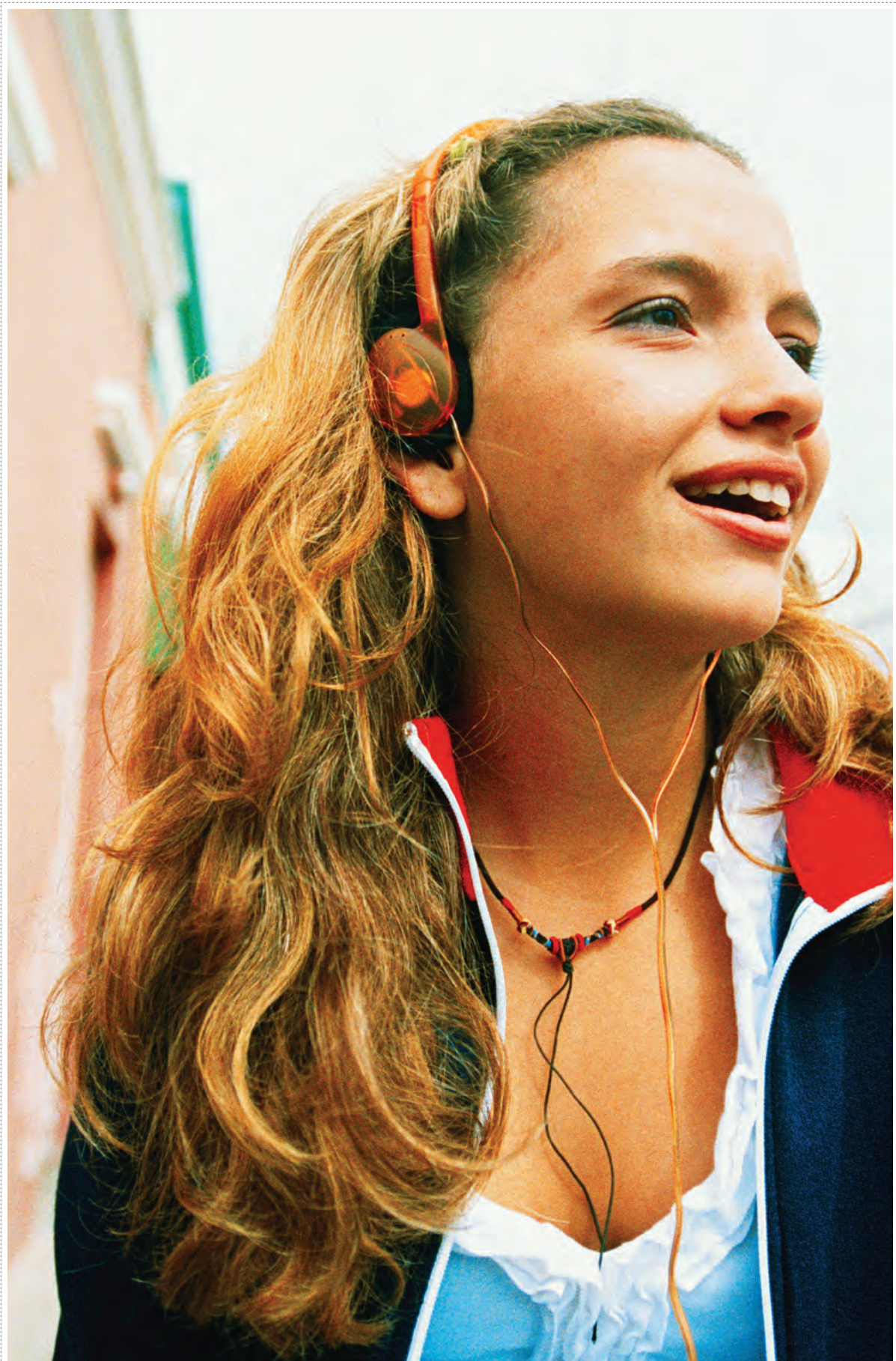
- ◆ THINK ABOUT ANOTHER TIME IN YOUR LIFE WHEN YOU WERE DEALING WITH CHANGE. Perhaps you are dealing with other transitions in your life right now like changes in education, family life, housing, friendships and financial stability.

What helps you through those changes? Make a list. Think about the people in your life that help you cope with transitions. Think about other things that pull you through like music, sports, relaxation, arts, writing, or talking to someone. Keep this list near you so that the next time you get worried about healthcare transition, you can look back and remember all of the people and things that helped you get through other transitions in your life.

◆ **For Youth**

Think about other responsibilities that you have in your life and that you have had to take on as you have grown up. Make a list of these responsibilities and think how you can turn your health care responsibilities into part of your regular routine.

- ✓ Complete assignments for school.
- ✓ Go to work.
- ✓ Babysit a younger family member.
- ✓ Cook dinner.
- ✓ Take care of a pet.
- ✓ Deposit checks in a bank account.
- ✓ Do housework.





FOR PROVIDERS

THINK ABOUT OTHER PATIENTS THAT YOU HAVE HELPED TRANSITION TO ADULT CARE, perhaps from other disease populations or from general practice. What helped them make that transition smoothly? What helped you to do it?

Make a list of solutions that you have used before, and adapt those for young people living with HIV. While this is a unique group of youth, many lessons can be learned from the transition to adult care for patients with pediatric or other special health care needs.

“A lot of the kids who transitioned really early on, they had a lot of anger at us because we were setting them up... putting them out into this adult world without any tools, and they were right.”

~ HIV PEDIATRIC PROVIDER

Coordinate Transition.

CONSIDER SETTING UP A TRANSITION COORDINATOR ROLE for someone in the young person's healthcare network that can work with both sets of health providers, the patient and his/her caregiver. This could be a social worker or case manager who already has or is quickly able to develop working relationships with everyone, in order to simplify communication between groups.

Things a transition coordinator can do:

- ◆ Help the young person practice taking responsibility for new tasks such as filling in paperwork, calling in prescriptions, and booking appointments.
- ◆ Help the pediatric provider develop a comprehensive health and social history of the patient to be shared with the adult care provider.
- ◆ Accompany the young person on his/her first visit to the adult health facility.
- ◆ Assist with communication between the patient or caregiver and health providers when necessary.
- ◆ Create a list of adult care providers and any important information about them to help the young person choose where to go for adult care.
- ◆ Assist with any changes in health insurance.
- ◆ Help the young person access peer support.

coordinate



build support

Provide Peer Support.

BY FAR, THE BEST PEOPLE TO LEARN FROM when it comes to issues like transition are peers. These can be other young people with HIV who have already transitioned into adult care and have advice to share, as well as teenagers who have not transitioned and are facing similar challenges and anxiety about the process.

Peer support groups and activities provide a forum for youth to share their transition experiences and support one another through this time. Peer support is also important for caregivers to hear from others who have helped their children transition to adult care.



FOR YOUTH

- ◆ IF YOU ARE A PART OF A PEER SUPPORT GROUP OR OTHER PEER PROGRAM, suggest to your facilitators that they organize a discussion around healthcare transition. Let them know what questions you have, or what you have experienced so that they can find the right people to answer your questions. Believe it or not, some of the best experts are likely to be your peers in the group!
- ◆ NOT PART OF A PEER SUPPORT GROUP ALREADY? Ask your health providers or social worker to help you access peer support in or near your community. Peer support can come in all kinds of forms—group, one-to-one, or online. Find out what options are available and link yourself up with the network that is right for you.
- ◆ HAVE YOU ALREADY TRANSITIONED TO ADULT CARE AND WANT TO SHARE YOUR EXPERIENCES WITH OTHER YOUNG PEOPLE? Just telling other youth about your experiences and giving some advice can make a world of difference in their lives. Ask your health provider about opportunities to help other young people have a positive experience with the transition from pediatric to adult care.



FOR CAREGIVERS

- ◆ **HAVING YOUR OWN GROUP FOR PEER SUPPORT** is also important! Seek out other caregivers who are living with or closely affected by HIV, to learn from and share your experiences with your child's healthcare transition. If you are struggling to cope with your child's diagnosis, your own diagnosis, or your child's adherence to medication, it may be too difficult to support him on your own. Seek help and advice from others who are going through the same situation as you are.

“Maybe his support group would have more impact on him than mom can right now. He needs to be able to talk with people in the same boat he’s in.” ~ MOTHER





FOR PROVIDERS

- ◆ IF THE YOUNG PERSON IS ALREADY PART OF A PEER SUPPORT GROUP, find out if they are focusing any of their discussions and activities on transition. If they are not, suggest to their leadership that they do.
- ◆ IF THE YOUNG PERSON IS NOT ALREADY PART OF A PEER SUPPORT PROGRAM, find out if there are any available in your local area or if there are virtual forums to connect the patient to.
- ◆ THINK OF ANY YOUNG ADULTS WITH HIV THAT HAVE ALREADY TRANSITIONED who you had in pediatric care or who you now have in adult care. Consider whether they could serve in a mentor role. If they are available and willing to speak with your patient, link them up. If they are accessible but not available to your patient, ask them for fifteen minutes of their time to interview them about their experience and any suggestions they would have for others, that you can then pass onto your patients.
- ◆ INTEGRATE MENTAL HEALTH SUPPORT into all peer support activities. Along with the many challenges that young people with HIV face, the process of transition itself can cause tremendous anxiety, warranting the need for individual and group mental health support options.

Focus on Adherence.

MAINTAINING ADHERENCE TO MEDICATION is a cornerstone of successful healthcare transition, but poses a number of challenges for young people during this complex time.

As young people grow into adulthood, they will take more responsibility for their medication but changes in lifestyle and relationships, not to mention the anxiety about increased responsibility, can cause some young people to stop taking their medications or disengage from healthcare completely.

While adherence is an outcome we are all trying to achieve, adherence is not an end result. Rather, it is a scale, upon which young people slide up and down over the course of their lives. Finding strategies to stay at the top of that scale, where a young person is proactively taking medication on time every-day, is critical.

adherence

“Even though
it’s not easy
taking the meds
every day,
trying not to
forget...it can be
done if I put my
mind to it.”

~ AGE 18



FOR YOUTH

Get to Know Your Meds One of the first and most important parts of living positively with HIV is that you understand everything about your medication and your health needs. This may be an area that a parent or caregiver took full responsibility for in the past, so you, your families and your health providers should work together to make sure that this information is shared. You should be able to answer the following questions:*

- ◆ What are the names of your medications?
- ◆ What are the reasons for taking each of these medications?
- ◆ What is the dosage for each medication (the amount you have to take and how often you have to take it)?
- ◆ Are there certain rules for taking these medications? These could include having to take them before or after meals, with liquids, or making sure not to take them in combination with other medications.
- ◆ Where do you go to get your prescriptions filled?
- ◆ Who is the doctor that prescribes your medication?
- ◆ What do you need to do to prepare for taking your medication when you are away from home? For instance, at school or work:
 - ✓ How will you carry them?
 - ✓ Do you need to carry water with you or is there water available?
 - ✓ Do you need to carry a small snack with you or is food available?
 - ✓ Will your medications be affected if it is very hot or very cold outside?
 - ✓ Do any medications need to be refrigerated?
 - ✓ What are your plans for taking medication if you are staying out overnight?



FOR YOUTH

- ◆ What do you need to prepare for taking your medication while on vacation?
 - ✓ How long will you be away from home?
 - ✓ Where is the best place to store your medication?
 - ✓ How are you going to remember to take your medication since you will be changing your normal routine?
 - ✓ If you are traveling with people and do not want them to see you taking your medication, what is your plan for taking it?
 - ✓ Will you need to carry water with you or will water be readily available?
- ◆ How do you store your medications and keep them organized at home?
 - ✓ Do you use a special container like a pill organizer with days of the week?
 - ✓ Do you have a separate container that you use to put your medications in when you go out?
- ◆ What do you do if you have other medications prescribed by a different doctor? Who do you ask?
- ◆ Can you smoke or drink alcohol when taking your medications?
- ◆ Do any of your medications cause side effects?
 - ✓ If yes, what are they?
 - ✓ Which ones do you need to call your doctor or clinic about?
 - ✓ What things can you do at home to help with these side effects?

* Adapted from “Transitions in Healthcare: A Guide for Teens with HIV/AIDS and their Families”, by the AIDS Alliance for Children, Youth and Families



FOR CAREGIVERS

WATCHING A YOUNG PERSON MISS HER MEDICATIONS, intentionally or not, can be very hard for a parent or caregiver. The best things that you can do are to stay positive, supportive and understanding during this difficult time.

- ◆ DO: Tell your child how much you love her and want her to stay healthy.
- ◆ DO NOT: Tell your child that she is going to die if she doesn't take her medicine.
- ◆ DO: Tell your child about your own experiences adhering to medications and what tools you have used to help you with your adherence (whether you are HIV positive or not, it is likely you have had to adhere to a medication plan at some point in your life. Share that experience).
- ◆ DO NOT: Threaten to or carry out pill counts when your child is not around. This could lead to a lack of trust between you.
- ◆ DO: Talk openly with your child about why he is not adhering and come up with some strategies together for making adherence easier.
- ◆ DO NOT: Punish your child for not taking medication.



FOR PROVIDERS

IF YOUR PATIENTS ARE ADHERENT:

- ◆ Celebrate them! Congratulate your patients and continue to encourage their adherence in every visit with them.
- ◆ Communicate openly with your patients about factors that may hinder their ability to adhere the way they have been (e.g. changes in housing, school life, relationships, etc) and develop strategies to maintain adherence throughout those life transitions.
- ◆ Remember to talk about safe sex practices as part of discussions on adherence. Young people should understand the implications for non-adherence on HIV transmission.

IF YOUR PATIENTS STRUGGLE WITH ADHERENCE:

- ◆ Talk to their social workers or case managers about developing a plan together, along with the patients, to ensure that they will take more responsibility for medication as they transition.
- ◆ Investigate options for taking fewer pills or once-daily medicine.
- ◆ Review and adapt dosing schedules to meet your patients' needs. Can they take their medication earlier or later in the day, around certain meals, etc?
- ◆ Investigate changes in delivery options for anti-retrovirals, like home delivery or clinic pick-up to mitigate your patients' fears of disclosure in the community.
- ◆ Provide adherence tools such as pillboxes, calendars and other incentives for optimal adherence.

Talk About Talking About It.

DISCLOSURE IS A MAJOR PART of living with HIV and should be a part of every discussion about positive health, dignity and prevention. Having a compassionate and trustworthy person to disclose to will improve adherence to medication and result in healthier decision-making. However, disclosure can be risky. There is still a lot of stigma and discrimination surrounding HIV in the world, meaning young people, caregivers and health providers should think and talk a lot about disclosure before making the decision to do it.

disclosure



FOR YOUTH

IF YOU ARE STARTING TO THINK ABOUT DISCLOSING your HIV status to someone, first sit down and think through the five “W”s. These should help you decide if disclosing to this person, now, is the right decision.

- ◆ **WHO:** Who is the person that you want to disclose to? Is it a family member? A friend? A boyfriend/girlfriend? Someone you want to be intimate with? Someone you have already been intimate with? A teacher? A neighbor? A healthcare provider? Is this person safe? Is there any possibility that this person will act violently toward you or betray your trust?
- ◆ **WHAT:** What do you want to tell this person? Do you want to talk about your HIV status and how you contracted HIV? If you do that, will be you be putting whoever transmitted the virus to you (e.g. a parent or a sexual partner) at risk? What other information do you plan to share when you disclose (e.g. that you want to have sex, that you think you have put someone at risk, that you have other STIs, etc.).
- ◆ **WHERE:** Where do you plan to disclose? Will you do it over the phone or in person? Over a text message or the Internet? Will you do it while you are alone with this person or when other people are around? What are the benefits to disclosing in that setting? What are the risks?
- ◆ **WHEN:** When do you plan to disclose? Do you plan to do it right away or after some time? Do you plan to do it around a sexual encounter?
- ◆ **WHY:** Why do you want to disclose? Is it because you feel you need to tell this person and can trust this person with this information? Do you want to have a sexual relationship with this person and believe they should know?



FOR YOUTH

If you are able to answer all of the questions on page 53 and feel confident about disclosing, there are a number of things you can do to prepare.

- ◆ **ROLE-PLAY.** The best thing you can do is practice. If you have someone in your life that already knows about your HIV status and is supportive, ask him or her to role-play the disclosure situation with you. This person could be a friend, social worker, caregiver or sibling. If you don't have anyone to help you out, practice in the mirror. You may feel silly, but having the conversation prepared in your mind will help you tremendously when you get into the real-life situation.
- ◆ **CHOOSE SOME "TESTING-THE-WATERS" QUESTIONS** to start out the disclosure conversation, so that you understand how much the person you are talking to knows about HIV/AIDS. You can ask these questions first, and depending on how they are answered, decide whether you want to disclose. These could include
 - ✓ Today in class we learned about HIV/AIDS. It was really interesting. Did you know that people could be born with it?
 - ✓ Have you ever taken an HIV test? Why or why not?
 - ✓ What would you do if a friend told you that they had HIV?
- ◆ **THINK OR TALK ABOUT** all of the possible consequences, both positive and negative, of telling someone about your HIV status. Are you comfortable with all of those consequences? Do you have a plan for managing each of those consequences?
- ◆ **IF POSSIBLE, TALK TO YOUR HIV POSITIVE PEERS** about their own disclosure experiences. They will be your best advisors. What did they do to prepare? Would they have done anything differently? What made it a good experience or a bad experience? Tap into the expertise of those that have been through this before, and remember to support other friends with their own disclosure situations when the time comes.

Only the Beginning.

THOUGH THIS GUIDEBOOK IS COMING TO A CLOSE, we want to remind you that this is only the beginning: the beginning of a thought, a conversation, a journey. Transition is a long process. It takes time, is continuous, and will constantly evolve as your life does.

In our talks with youth, caregivers and providers, we learned a tremendous amount about the concerns that everybody has about healthcare transition. However, we also learned that when people start brainstorming together and communicating with one another, they are often able to come up with brilliant ideas.

If there is one key lesson to take away from this book, it is that communication is really important. Start the conversation early and make sure that all of the right people are part of it. This will ensure that healthcare transition is not only successful, but that it serves as a model for all of the changes that a bright and healthy future will bring.



FOR YOUTH

Take Charge of Your Health Care!

SOLUTIONS AT A GLANCE

- ◆ Start conversations about transition early and have them often.
- ◆ Learn about HIV, how it affects your body and what you need to do to stay healthy and strong.
- ◆ Slowly shift the responsibility for healthcare from the health provider and caregiver to yourself. Practice calling in prescriptions, going to the pharmacy and filling out medical forms.
- ◆ Know who to call in case of an emergency and carry that information with you.
- ◆ Prepare health histories and questions for a new adult health provider.
- ◆ Communicate with one another!
- ◆ Take a tour of the adult healthcare facility and meet your providers before entering care.



FOR YOUTH

- ◆ Build on past successes with other life transitions.
- ◆ Build a support network of people that can help you through transition. Make sure you have peer support.
- ◆ Meet privately with your healthcare providers. Write down your questions and ask them!
- ◆ Ask for copies of medical tests and reports. Keep these in a safe place, along with all of your important health information.
- ◆ Know what medications you take, when you take them and where to get them when you need refills.
- ◆ Know your insurance details and how to get a referral.
- ◆ Talk to your doctor and social worker about “other stuff” like relationships, birth control, violence, and sex.
- ◆ Love yourself; embrace transition!



ACRONYMS & DEFINITIONS

HIV: Human Immunodeficiency Virus.

Adherence: Taking medication as prescribed, over the long-term.

AIDS: Acquired Human Immunodeficiency Virus.

Perinatal HIV Infection: Infected with HIV at birth.

Health Provider: Anyone that is responsible for the medical and/or psychosocial care of a young person. This can include primary care and other physicians, nurses, social workers, mental health professionals and case managers.

Pediatric provider or pediatrician: A doctor who takes care of babies, children and teenagers.

Internist: A doctor who is trained to take care of adults.

Specialist: A doctor who treats one kind of health problem or one part of the body.

STI: Sexually transmitted infection.

Caregiver: A parent or legal guardian.

Families: Families come in all different forms. Some teens live with one or both parents; adoptive, foster or stepparents; grandparents; other relatives; or friends. “Families” in this book can mean any of those situations.

Young People: The terms “youth”, “young people”, “teenagers”, and “adolescents” are used interchangeably in this guidebook. They represent the broad range of ages when healthcare transition takes place. Planning for transition can begin as early as 12 and take place from late teens to early twenties.

Healthcare Transition: The process of leaving pediatric doctors and nurses, and getting care from a doctor who is trained to work with adults.

resources:

THE HEALTH INSURANCE SYSTEM IN THE U.S. IS EVER-CHANGING and can seem very overwhelming and complex. Even health providers have a hard time understanding it all. It is important for young people living with HIV to understand how their insurance options may change as they transition to adult health care, including what benefits they are eligible for as adults and those they may lose after leaving pediatrics. Social workers and case managers can play a key role in staying on top of these changes and assisting their clients through the process. Young people should be encouraged to understand this information from an early stage, practice filling out paperwork and carrying important insurance information around with them.

Here is some important information to get you started:

Insurance and Benefits.

Health Care For All offers a HelpLine that is a free resource available to everyone. The HelpLine is here to answer your questions about health coverage in Massachusetts. They can answer general insurance questions, tell you what free and lower-cost programs you may be eligible for, and help you to apply. For more information, call (800) 272-4232 or visit www.hcfama.org.

MassHealth is Massachusetts' Medicaid program—a federally-funded, state-run program that provides medical services for individuals and families with limited income and resources. Call (888) 665-9993 or 800-841-2900 or visit www.mass.gov/masshealth.

Massachusetts HIV Drug Assistance Program (HDAP) provides free medication for those living with HIV/AIDS, who are under or uninsured. Visit www.crine.org or call (800) 228-2714. TTY: (617) 778- 5460.

Supplemental Security Income (SSI) is a federal program for people who are disabled and unable to work full-time. Call (800) 772-1213 or visit www.ssa.gov.

Health Information.

HIV/AIDS Hotline (AIDS Action Committee) offers information, support and referrals regarding HIV/AIDS, STDs, hepatitis and sexual health. Visit www.aac.org or call (800) 235-2331. TTD/TTY: (617) 437-1672.

Maria Talks (a program of AIDS Action Committee with support from the Massachusetts Department of Public Health) is a sexual health information campaign. Launched in 2008, it provides relevant, medically accurate sexual health information and resources to teens AND providers who work with youth across the state. Some of the issues they address include information and referrals on sex, birth control, pregnancy, STI and STD, sexual violence, substance abuse, and GLBTQ information and programs. For more information, visit www.mariatalks.com or call (877) MA-SEX-ED (627-3933).

Massachusetts Department of Public Health:

Office of HIV/AIDS provides a range of services including prevention and education, HIV antibody counseling and testing, client services, health and support services. Find links to important resources at www.mass.gov/dph/aids or call (800) 443-2437.

Massachusetts Department of Public Health:

Children and Youth with Special Health Care Needs Program

works with families, providers and others to support children and youth with special health care needs and partners with families to ensure policies and programs meet their needs. Call their Community Support Line at (800) 882-1435. TTY: (617) 624-5992. Or visit www.mass.gov/dph/specialhealthneeds.

Transition Information.

Got Transition? (The National Health Care Transition Center) is a national resource for health care professionals, families, youth and state policy makers focusing on a young adult's transition from pediatric to adult health care. This site serves as the basis for an information exchange about health care transition, particularly as pertaining to youth with special health care needs. For more information, visit www.gottransition.org or call (603) 228-8111.

Healthy Transitions: Moving from Pediatric to Adult Care (The New York State Health Institute for Health Transition Training) teaches skills and provides tools for care coordination, keeping a health summary, and setting priorities during the transition process. Their web site features video vignettes that demonstrate health transition skills and interactive tools that foster self-determination and collaboration. For more information, visit www.healthytransitionsny.org or call (315) 464-7561.



credits:

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www.mass.gov/dph/masscare



Next Step

Next Step shatters limitations and elevates aspirations of teens and young adults living with life threatening diseases.

www.nextstepnet.org



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