



# *Let's Talk About It*

**A Calendar of Recommendations  
for Professionals Working with  
the HIV Community**

# Who are the LTAI Peer Advocates?

"Let's Talk About It" (LTAI) is a peer positive advocacy program whose members are HIV-positive women and female caregivers in North Florida. This diverse group of women meets monthly to support and encourage one another while building skills to reach out to their peers and providers in North Florida.

The Peer Advocates are active in the positive community as well as the larger communities in which they live. They have developed a magazine, resource guide, HIV testing posters and library exhibits to educate their communities on HIV and have presented their perspectives at various community and UF events. All in all, **the Peer Advocate's mission is to be a voice for women living with HIV; bringing the topic of HIV and living with HIV out of the shadows and into the spotlight.**

The LTAI Peer Advocates are always interested in speaking to community and healthcare groups in North Florida. If you would like to request a presentation or any of our materials, please contact us at: 352-372-1095.



## Let's Talk About It

A Calendar of Recommendations  
for Professionals Working with the HIV Community

**What:** This calendar is meant as a resource. Each page shares a series of recommendations to improve the relationships between medical and social service professionals and the HIV positive community. These are collective experiences expressed through individual voices.

**Why:** The Let's Talk About It Peer Advocates are committed to improving the interactions between people living with HIV/AIDS and medical and social service providers. Disheartened by negative experiences, these Peer Advocates want to use their voice and invite professionals to hear positive women's perspectives.

**Who:** This calendar is meant for anyone working with the HIV community. From doctors, to nurses, to social workers, case managers and beyond, there is a message here for everyone. Let this calendar be a daily reminder of the voices and needs of those that you are serving.

## Do no harm...

“Some days I feel that the medical community is failing us. I might have known about my HIV status sooner, if only a doctor had advised me about getting tested. Before I was diagnosed with HIV I suffered for over 18 months with thrush, not knowing what was wrong with me; my symptoms getting worse by the day. I eventually lost all of my ability to taste and went to a clinic for help with this issue. The PA examined my mouth and suggested several blood tests, including an HIV test, to which I agreed. A few days later I went back to the clinic and was informed that I was HIV positive. I was in shock! After the additional blood tests, I was told I could have had **undiagnosed HIV for 6-10 years**. My CD4 count was at 12 and my viral load was over 157,000. **I had AIDS!**

I saw many doctors over the 6-10 years prior to my diagnosis. I believe my previous doctors looked at the number of years I was married and disregarded the thought of offering me the HIV test—even during my annual check-ups. This is a big problem and it may be why older women are diagnosed so late with HIV. **A long-term marriage or relationship does not protect us from contracting HIV.**

Doctors, you are harming your patients when you don't offer HIV tests! I know that we as women have to take responsibility for our own health, but many women won't ask about the HIV test because they are too embarrassed. We rely on you - your education, training and expertise. Doctors **need** to be offering HIV testing to **ALL** their patients, it's part of their responsibility, it's part of their oath, 'Do No Harm.' ”

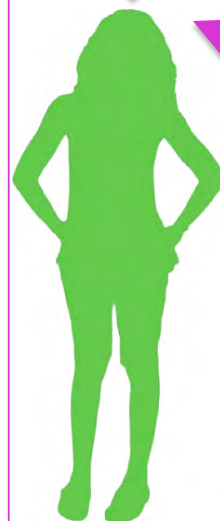
*Many women won't ask about the HIV test because they are too embarrassed.*

## Peer Advocate Recommendations

Practitioner, start a conversation with each of your patients about the importance of HIV testing.

Offer HIV testing to every patient in a kind and respectful way, regardless of age or relationship history.

HIV is a chronic disease. Don't let stigma cloud the provision of care.



## September 2013

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
1	2 Labor Day	3	4 Rosh Hashanah (begins at sunset)	5	6	7
8	9	10	11	12	13 Yom Kippur (begins at sunset)	14
15	16	17	18 National HIV/AIDS and Ageing Awareness day	19	20	21
22	23	24	25	26	27 National Gay Men's HIV/AIDS Awareness Day	28
29	30					

## A dose of dignity...

“How about a dose of dignity? All patients, especially those living with HIV, deserve to be treated with respect, dignity and kindness. Too often, women living with HIV are made to feel as though they **deserve to be sick, that it is their fault for having this disease.** No one should be made to feel this way, especially not by those in the medical community. Please understand that the underlying assumptions you have about me- about how I got the disease, what sort of lifestyle I lead- *I see those assumptions* in the way you look at me, speak to me, and interact with me. From the minute I walk into the doctor's office and speak to the receptionist, to the time I walk out that door, I **deserve to be treated as a human being by each and every member of the staff, not as your assumptions dictate I am.**

We need the kindness and support from our entire medical team. Please put yourself in the shoes of someone living with HIV. How would you want to be treated if the roles were reversed? **We are not our illness.** Treat us with the same dignity and respect you would want to be treated with, HIV positive or not. ”

*Treat us with the same dignity and respect you would want to be treated with, HIV positive or not.*

## Peer Advocate Recommendations

Provide sensitivity training to all members of your clinic staff on how to interact respectfully with HIV positive patients.

How I became infected may have little to do with the person sitting in front of you today. Respect me.

Next time you are interacting with an HIV positive patient, put yourself in their shoes and think about how they might be experiencing their entire medical visit.



## October 2013

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
		1	2	3	4	5
6 Daylight Savings Ends	7	8	9	10	11	12
13	14 Columbus Day	15 National Latino AIDS Awareness Day	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30	31 Halloween		

## Treating ALL of me...

“I have a physical illness: HIV. I get it. But my health is more than just physical; it is also my **emotional well being**. I feel so often that doctors focus on the physical, and on medication adherence. But, even I know that my emotional health affects my treatment adherence! As my doctor, **I need you to ask me about my home life, how I am coping with daily stresses and struggles**. Don't just skip straight to the physical stuff.

**I know you can't solve all my problems, and I'm not expecting you to.** Sometimes I just need some **encouragement**.

Encouragement to get me involved in local support groups where I can connect with others, encouragement to seek out mental health counseling. You don't have to push, but a little encouragement goes a long way. Let me know that you care about all of me, that you're not just checking off boxes when we met.

**Make my emotional health part of every one of my appointments.** The outcome will be a positive one. ”

*I know you can't solve all my problems, and I'm not expecting you to. Sometimes I just need some encouragement.*

## Peer Advocate Recommendations

Don't treat me like a number - let me know that you CARE.

Make my emotional health a priority for each one of my visits.

Be aware of local resources and support groups that can help me. Have some of their information on hand to share with me.



# November 2013

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
					1	2
3 Daylight Savings Ends	4	5	6	7	8	9
10	11 Veteran's Day	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27 Hanukkah Begins	28 Thanksgiving	29	30



## No more excuses...

“ I am an HIV positive woman and in 2011 I was referred to a surgeon to have a hysterectomy. Upon meeting the surgeon, she kept pushing me to have a different procedure, a procedure that was not recommended to me by my gynecologist. I told her I intended to adhere to my gynecologist's recommendations. The surgeon finally told me why she preferred the alternate procedure - **because she was worried she would a needle stick and become infected with HIV.**

This surgeon was trying to get pregnant and did not want to contract HIV. She said she would have to find another doctor who would do the surgery with her so she would not be at risk. **Remember, this is just 2 years ago!** I thought to myself, **doesn't she know about universal precautions? How not to get infected?** I could not believe that in this day and age a doctor would say something like that to a patient. It felt like a resurfacing of the stigma I experienced 30 years ago, when I was first diagnosed. Back then, I could understand that sort of stigma, but today, when we've come so far and so much is known about HIV? HELLO! There is no reason this should still be going on. **It is unacceptable.**

Stigma in the clinical setting is a big deal. **A lot of patients feel forced to sweep it under the rug, make excuses for it or ignore it; but this has to stop. We have to draw the line.** We need to educate all health care providers about HIV and AIDS. If they are scared to do a procedure on us, what is that telling us? The education needs to begin now! ”

A lot of patients feel forced to sweep it under the rug.

## Peer Advocate Recommendations

All health care professionals need to be trained in universal precaution measures.



All medical settings should instill policies requiring all employees to participate in continuing education courses related to HIV.

## December 2013

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
1 World AIDS Day	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25 Christmas Day	26	27	28
29	30 New Year's Eve	31				

## Where do I go from here...

“When I found out that I was HIV positive, I hoped that medical and social service providers would be able to help me navigate the system. But, I found that was not the case. It took me almost a year before I truly understood the benefits of Ryan White and other social services.

During that year, yes, I received packets of information about programs from my case manager and other service providers. But what was so confusing for me were the **steps you need to take to get into many of these programs**. I had a ton of information, but I wondered what to do with it? Where do I go from here? And even when “supposed solutions” were offered, they seemed like dead-ends. I was referred to programs that I did not qualify for; doors were closed with no one to help me find another option. At one point I remember thinking to myself, ‘these people are supposed to help me, but I’m stuck in the same place I was in before I met them.’

It shouldn’t have to come to a point where you lose hope. There are so many resources available to those living with HIV and we need the medical and social providers around us to **help us navigate** those systems. **Assist us with helpful solutions that make sense with our realities**. Provide us resources that are helpful to **our unique needs**. We need your assistance navigating these systems.”

*What do I do with this?  
Where do I go from here?*

## Peer Advocate Recommendations

Have a dialogue with me to truly understand what my needs are.



Don’t overwhelm me with packets of information that do not apply to me. Help me sift through the information to see exactly what services offered apply to me.

Help me navigate the system. That may mean helping me make that first phone call, etc.

## January 2014

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
			1 New Year's Day	2	3	4
5	6	7	8	9	10	11
12	13	14	15	16	17	18
19	20 Martin Luther King Jr. Day	21	22	23	24	25
26	27	28	29	30	31	

## Stranded in the water...

“I am a woman living with HIV and I try my best to adhere to my ID doctor's treatment. However, sometimes I get sick and end up at the emergency room. In those moments, I need the ER physicians that I interact with to **actively communicate** with my ID doctor about my treatment and care.

I have had experiences when an ER doctor would change my HIV medications, and it makes me worry. Then, when I go to my next ID appointment, my ID doctor is frustrated and wants to know why my medications were changed. **Imagine how I feel as the patient!** My meds being changed over and over again, and me, the patient, sick, stuck in the middle of two doctors who are not communicating with one another.

Please understand, that as a non-ID doctor, you are seeing me at one point in time. My ID doctor knows my entire HIV history and what is normal for me. Before changing my medications to treat my momentary problem, please consult with my ID doctor. Putting something in my electronic medical record is not consultation. **That is simply informing; not consulting.** Please, don't leave me stranded in the water. I need you to communicate with my ID doctors so we are all on the same page about my treatment and care. ”

*Imagine  
how I feel  
as the  
patient!*

## Peer Advocate Recommendations

Actively communicate with my ID doctor to understand my current treatment.



Keep me involved in the process so that I know what is happening, why things are changing, etc.

Listen to my voice as the patient. I, too, bring my knowledge of my medical history to the table.

## February 2014

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
						1
2	3	4	5	6	7 National Black HIV/AIDS Awareness Day	8
9	10	11	12	13	14 Valentine's Day	15
16 President's Day	17	18	19	20	21	22
23	24	25	26	27	28	



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# HIV Community Groups in Alachua County

## Let's Talk About It

- An HIV advocacy group for HIV positive women and female caregivers. Women meet monthly to encourage one another and build skills to reach out to serve their peers and community.
- Days: First Monday of each month
- Time: 5:30pm-7:30pm
- Location: Call for location
- Contact: 352-372-1095

## Peers Empowering Peers (PEP) Club

- An HIV support group for people living with HIV and people affected by HIV. Educational topics each month and community events.
- Days: Last Friday of each month
- Time: 11am-1pm
- Location: Alachua County Health Department
- Contact: 352-575-7352

## Gainesville Area AIDS Project (GAAP)

- A safe haven where people with HIV/AIDS and their loved ones can gather in a friendly atmosphere free from discrimination and stigma. Provide weekly lunches and facilitate TREE program (distributing toiletries).
- Days: Every Tuesday
- Time: 12:30pm
- Location: 3131 NW 13<sup>th</sup> St. Gainesville, FL
- Contact: 352-373-4227

## Positive Attitudes

- HIV positive men's support group that offers education, hope, companionship and encouragement for men living with HIV. This group focuses on living positively with HIV and extends support and friendship.
- Days: Every 2<sup>nd</sup> and 4<sup>th</sup> Wednesday
- Time: 5:00pm-7:00pm
- Location: Call for location
- Contact: 352-334-7960

\*Note: Dates and times are subject to change. Please call before attending any of these meetings.

For more information on groups in other Area 3/13 counties, check out: [www.313hiv.com](http://www.313hiv.com).

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