

Program Script for Arzu Kaykı (Aired on 31 January 2010)

Category: Health

Location: İstanbul

Einstein had a famous saying, “Breaking an atom is easier than breaking prejudice”.

Today we will talk about someone who’s job is harder than trying to break an atom to pieces.

AIDS is a subject most do not want to discuss. We want to bring you the story of those who seek to raise public awareness about AIDS.

Putting prejudice aside, they are the ones that fight and stand by those that have been left alone...

Interview: Arzu Kaykı

Turkey is misinformed about HIV/ AIDS. Parents won’t send their children to the same school as a victim, and why is that? There really is no reason but just is so...

Or there are doctors who won’t treat, lawyers who won’t take their cases, people who won’t even want to live in the same neighborhood.

Actually these are all signs of being ignorant about the disease. I have a friend in Botswana who also has projects similar to these.

He says: “In Botswana people that are HIV positive are looking after my kids. Everyone has baby-sitters who are HIV positive looking after their kids.”

Because there are so many people living with HIV. We here in Turkey don’t know as much because we think that there are not so many cases.

And whatever we hear about AIDS is usually about death, about people being sick and skinny.

It’s frightening. But when we ask, no one knows really what it is. And because we don’t know, we refuse it whenever we come across it.

We do not consider whether we are preventing them from having a family, or from working, or from having a normal life. We just say “as long as they stay far from me” ...

Our objective is to change this panic approach and give the public logical and viable answers.

We shouldn’t be prejudice against these people. There is nothing medically preventing them from living their lives even though they are HIV positive.

There is nothing preventing them either from having a normal social life. They can live as if they had any other chronic disease.

Actually these are all fictitious stories that we have in our minds, stories that we have read in newspapers, gossip stories, emails.

That we could catch it from the money we touch, from where we sit, just a bunch of wrong facts. We have to replace these thoughts with true facts about the life of a person who has HIV positive.

Our wish is to have these people live a normal life like everyone else.

Turkey’s biggest problem is that we have been misinformed about HIV and AIDS.

Everyone is afraid of AIDS but very few know what they are afraid of.

Interview: Arzu Kaykı

HIV, Human Immunodeficiency Virus, is a virus that damages the human immune system. HIV is a virus that is in our body.

It’s a virus that can’t pass from humans to animals, from animals to humans. It is acquired through contamination.

At birth the virus can be transmitted from mother to baby via blood or other bodily fluids.

It can also be transmitted via unprotected sex.

Once this virus has entered the body, it attacks the immune system and eventually causes it to weaken.

HIV is the name of the virus. AIDS is the name for the whole syndrome. After the immune system becomes weak, the body is defenseless.

AIDS stands for Acquired Immunodeficiency Syndrome.

When the immune system is down, many diseases, viruses could enter the body. The system breaks down, the person becomes weaker.

That period, from when the HIV enters the body, can last sometimes 3 sometimes 10 years. After the virus appears, it is from that point on that it is called AIDS.

Arzu Kaykı is a young environmental engineer. After she finished her masters in Industrial Engineering at Bosphorus University she realized she had two choices.

Either she was to start her career as an industrial engineer or she would work with NGOs and change the lives of others. She chose the second path.

Interview: Arzu Kaykı

To be helpful is a great feeling that has been my mission since I was a child. I always wanted to feel helpful, when they asked me “what do you want to do when you grow up?” I would answer “I want to be helpful.”

I mean, I want to add value. I realized this when I was studying to be an industrial engineer.

As an industrial engineer, your objective is to take something and optimize it.

If I had stayed in that sector, maybe I would work to increase usage of machines thus making jobs redundant. Maybe this is just a simple explanation but I just want to be helpful to people’s lives.

I want to use that mentality. You know, doing so much with so little money with optimization.

That’s what I want to do for people’s lives.

Here I can see that I am able to do this therefore I am happy.

While Arzu Kaykı started volunteering for NGOs, she realized that there wasn’t even an organization for AIDS.

She decided to further her studies and pursue volunteering in that direction.

What once started as an email group is now known as the Positive Living Association.

Interview: Arzu Kaykı

At the start of the association, there was an e-mail group. We still have an e-mail group called HIV positive.

A friend first started this email group because at the time he could not find support from anywhere, could not find anyone to share his thoughts and concerns with so he decided to start an e-mail group.

Slowly other friends started to join, then doctors, then activists and eventually the association idea came up.

The Positive Living Association is a place that everyone can contact for information and support about AIDS.

They can get information about the procedures that the patients with HIV positive have to go through as well as organize informational meetings about HIV for universities and companies.

The most important working part of the association is the Positive Living Support Centre.

Interview with Arzu Kaykı

The Positive Living Support Centre was the first and most important service of the Positive Living Association.

Why did we start with such a support centre? Because we see that those who have been diagnosed with HIV confront serious prejudice.

We are trying to change this.

We are trying to tell people with HIV that they are not going to die, that they have equal rights as everyone else.

If they have been subject to any sort of prejudice after being diagnosed, we give them psychological support.

And we also offer support if they have problems in obtaining medication or social security.

There is a huge need for this service. Our association’s aim and objective is primarily to support people with HIV.

And with this in mind we founded this association. **Our center started in 2006.**

Till today we have supported 530 patients with HIV. For example providing psychological, legal,

medial and nutritional support, as well as access to medication, and other information such as social security.

Since day one, we have continued our support through this centre.

While working at the centre, we also had a chance to see where the problems were.

Why is that we see HIV more common among certain groups? For example, we started seeing it among a lot of sailors.

They are constantly getting tests done but not being informed and are getting fired.

Or we see incidents where a people’s rights were violated by the media. Where do people with HIV face problems?

We engage in advocacy on different topics, and throughout work we’ve started to see more clearly where the problems are.

In hospitals, at the dentist... HIV positive patients are facing discrimination.

We have seen cases where we intervened when a birthing clinic did not take a patient or if a birthing clinic is being prejudice toward the new born baby.

By intervening, we help the patient and also help any future patients that face the same situation.

We do what we can so that they do not have the problems that previous patients went through.

While doing this, we have also worked to develop other projects around prevention. We give seminars to university students and lawyers.

We talked to people about HIV/ AIDS and worked on changing the public’s perception.

We focused on the media with training, projects, meetings to correct the wrong usage of words.

We try to make news about people with HIV more positive and fair.

We bring to life many problems that we have seen in our support center and that form the basis of our work in the field.

We started a Legal-aid project. With this project we give people with HIV education about rights as well as legal support...

We help them through legal actions they need to take.

Actually these are mostly the first cases in Turkey and since they are seen as precedents, these are in some ways are setting the basis for the legal decisions regarding this subject in Turkey.

AIDS patients are alienated when they reveal their disease. Being alienated is one of their biggest problems.

Because of incorrect and incomplete information, people don’t want to be neighbors with people living with AIDS or even shop around them.

So as not to make their life in society any harder than it is, we have decided not to interview any of these patients.

Behind the camera they talk about all the problems they have come across. They are afraid of being alienated so they don’t want to talk in front of a camera.

So decided not to show or ask AIDS victims for an interview to respect of how hard their lives already are.

Interview with Arzu Kaykı:

The aim of the association is so that these people will not need such as association in the future. Not in Turkey, nor in the world. Our work should ideally eliminate discrimination so we don’t have to fight for their rights.

At this point we are all, me, you, we are all positive.

We easily talk about it while drinking tea. But unfortunately, in the past, so many of our friends have come across tough situations in the media and it was hard having to reveal this.

So many implications like not being accepted to a school, to a job, to a hospital.

It’s sad when you need something the most and can’t get it because you are HIV positive.

Those with HIV are discriminated against in a way others with different contagious illnesses are not. It has a stigma.

Not only in Turkey but across the world...

That is why people living with HIV do not in any way want to reveal their identities. Their children will have problems at school;

their neighbors will have confrontations in the neighborhood, the market won’t sell them bread, the butcher won’t sell them meat. To avoid problems like these, people with HIV prefer to stay anonymous.

Of course as we become more aware we will be ready for this. No one needs to know who has what health problem,

however we believe that we will be in a place where we can easily talk whether we have HIV or not. This is our goal...

The Positive Living Association staff and volunteers give support to people with HIV and they want to eliminate all prejudices against them.

The wrong idea that AIDS can be contracted very easily has spread and this makes it even harder for these patients.

While the Positive Living Association leaves the struggling with this disease to medical science, they feel it is their responsibility to give the public correct information and help patients through legal support.

Interview with Attorney Habibe Kaya:

First of all, the patients do not have to share their diagnosis with anyone else.

This is doctor/patient confidentiality. The doctor cannot share this information with anyone without the patient’s approval.

This is their basic right; however we have come across horrible examples. For example, the doctor telephoning the patient and giving the results over the phone, or calling the gendarmery and informing them.

We’ve seen these horrible things happen.

But it is happening less and less, and the doctors are becoming more sensitive.

I say first and foremost, get the right information. Then comes respect to basic rights. Discrimination is penalized in the Turkish criminal law.

It is against ethical principles of any profession. It is against all of the international conventions that Turkey has signed. It is against our constitution.

Everyone should be aware of discrimination laws and that no one can act according to their own rules. There are laws to prevent discrimination.

We are trying to develop this sensitivity but everyone needs to be informed properly. For example, tragically some doctors

even state that the disease can be transmitted by just being in the same room, imagine how a co-worker of a HIV victim would feel upon hearing this.

In one case, the attorney general compared having HIV/AIDS to having rabies.

Not having the proper information can even pave way to violation of rights and misleading the justice.

So everyone needs to be informed about AIDS, they need to know the legal rights of the patients and have the get the real facts from the right place.

Interview with Arzu Kaykı:

Before establishing the association, we heard such horrible stories about women forced to give birth to dead babies.

Of people not being taken into intensive care units, people being left for dead.

But we see that we have made a difference. We saw that we can hold the hand of a person who is about to commit suicide.

We saw the happy look on the face of parents diagnosed only 9 months ago and just gave birth. We saw the joy they shared in having that baby.

We hear of **people who were diagnosed over 13 years ago and done absolutely nothing about it** and then we hear that these **people now come here for support and have decided to accept treatment.**

With every case we work with, and maybe even through this TV program, we have the chance to touch the life of someone new.

We even have people come back to us saying things like “my cousin is HIV positive, I was very cruel towards him,

“I behaved badly, I had my prejudices. But now I regret this so much.”

Relationships can be healed; people’s lives can be touched in a positive way. That is our most important contribution here...

Arzu Kaykı has picked a minefield of a field to work in, one which many would want to even talk about.

She has approached AIDS as a knight in shining armor. She has tried to replace the mountain full of false assumptions with correct information.

She goes on to mention that people living with AIDS are not alone and has made a big difference in everyone’s lives who had proper information about AIDS.

What do you think of that? Arzu Kaykı really has worked hard and put up a huge struggle but she is seeing that it’s not for nothing.

As you can see, if you do something right, if you put your heart into it, give it your all, you will see.

No matter where you are, in Turkey, or on earth, one day we can call on you.

If you are wondering how you can be on the Turkey’s Changemakers program, I will tell you after a short break.

We are at the SEED Conference Center of Sabancı University Sakıp Sabancı Museum in Istanbul.

We present Turkey’s Changemakers here but we search high and low throughout Turkey for these names.

If you feel there are Changemaker’s around you, please contact us.

It’s very simple. Go to our website www.farkyaratanlar.org and fill out the form.

Or you can call us at +90 0212 249 23 14. Our friends will direct you.

Dear Viewers, please watch and recommend to others to watch the only program in Turkey that gives good news. Until we meet at a new Turkey’s Changemakers program, I’m Cüneyt Özdemir, wishing everyone a good evening.