

OVER CUPS OF TEA

Tea in India is what people choose to make it. Up North, in the cold recesses of Leh and Ladakh it's almost a soup, brewed with salt and yak's milk, in the plains the beverage is a sweet, creamy concoction spiced with cardamom or ginger. In the East, they prefer the liquor with a spot of milk; in the South it is the milk that gets a spot of liquor.

Chai, Cha , Chai-ya... whatever the be the name of this magical brew, tea is the warmth that tightens bonds and loosens tongues across India. Every guest worth his welcome gets a steaming cup. Tea stalls dot both the city as well as the deepest recesses of the rural landscape; it is here that governments are torn apart, the latest cricket match dissected, the state of youth disapproved of and bets hedged on whether a certain star will change his hairstyle once again for the next film.

It seemed natural therefore that a Family Case Manager (FCM) with Balasahyoga at Kurnool think of a steaming cup waiting for him at *Ramja Bi* his first client for the day. Though feisty and inclined to be stubborn, she was nevertheless vivacious and generous in her hospitality.

But that morning when he entered her modest one room home, all he got was a steady stream of scalding abuses. And the choicest ones at that, he recalls grinning.

The angry woman

" She called me names, you'd blush to hear. And she wouldn't let me get in a word sideways. I was a bit nervous you know, people would start thinking I had been up to some mischief. So like a timid mouse I kept backing inch-by-inch towards the door not quite sure whether she'd take the saucepan and pound my head into mincemeat. She was like a woman possessed. But her steam blew off and she cooled down in some time; then she told me what had irked her. Till she did I had to stand my ground, literally. These are occupational hazards of my job," he adds laughing.

So what had irked her?

You see we had sent her for ART after a lot of counselling. She is a widow and trying to put two daughters through residential school. Her youngest child, a boy, is positive like her and enrolled for a Residential Bridge Course. It is important for her to be healthy and work regularly so that she can be there for them.

Ramjabi cuts in with a look of mock anger:

Look at him the glib talker...how smoothly he talks...that is what convinced me to join ART. But after I started taking the drugs I was horrified. The pills left me nauseated, weak and unable to do the most basic thing like stand on my two feet. And to think I used to work as a domestic help in ten houses before I took those horrible medicines. While the doctors and the FCM had both told me about possible side effects, nothing had prepared me for the degree of discomfort. I stay alone, so you can imagine how terrible it was for me. I could have killed this FCM here for having put me through the ordeal. I stopped taking my medicines and made up my mind that if he ever stepped into my house I'd cut him into small pieces and invite the neighbourhood dogs for a feast.

The FCM is obviously a brave man and weathered many a Ramja Bi storms. He merely grins at her recollections.

She had not only stopped taking her medicines but also become paranoid. The very mention of drugs would bring on a bout of neurosis and violent one at that. Every one at Balasahyoga was worried and we just did not know what to do with her.

ART adherence in patients often falls because of the side effects of the drugs. From nausea to skin rashes to diarrhoea, patients react differently and with different intensity. The best thing to do is ride the bad patch taking whatever supplementary medicines are needed to minimise the discomfort. With time the body gets used to the drugs. In cases of severe side effects, doctors change the drug combination. It is by trial and error that the doctor arrives at a combination that works well for the patient.

However most people who experience some side effects, however bearable, give up the medicines because they feel that the drugs are harmful and make them sick. Most are so distraught by their experience that they do not want to give either the doctor or themselves a chance by going in for a changed combination. Repeated discontinuation of the first often leads to the first line drugs becoming ineffective and hastens the introduction of the second line.

It is imperative to keep the patient motivated enough to give the first line an honest try; more so because the second line is not available free of cost and a failure in second line leaves the patients with no medical alternative.

Ramja Bi was just not willing to give a different first line combination a try. And Balasahyog could not let her be. It was a battle of wills, where Ramja Bi had a big advantage. It was her life and she had

the right to decide what she wanted to do with it. The only option seemed to be to counsel her and make her see light.

At this point it is important to mention that counselling is the backbone of the Balasahyoga programme. While HIV- affected families are treated as unique cases and solutions and services are tailored for each, extensively counselling is a common thread.

With Ramja Bi, the Balasahyoga team decided to try a multi- pronged counselling approach to tackle her paranoia. The FCM increased the frequency of his visits along with the counsellor; believing persistence would make her see sense.

“ After a couple of visits when all we got was a volley of abuses, the customary cup of tea started to make its appearance. That’s when we knew we were making a headway.”

Whenever she visited her son at the RBC run by the same sisters (VWCS) who are implementing Balasahyoga in Kurnool, she would be shown other PLHIV (there is also a Community Care Centre within the same premises) who had faced similar problems but overcome them.

Even the ART staff had been roped in to counsel her and they did it with great zeal.

By Ramja Bi’s own admission, it made a difference to her thinking.

The doctor also talked of change combinations. Plus everyone at Balasahyoga was always talking of giving my children and myself a chance. Slowly I had to admit to myself that these people stood to gain nothing by putting up with my pig-headedness. They were not even my family and if anyone stood to profit it was me. So I went back to the ART centre and started off with a changed combination.

Did that work? Does she still take it?

“ Well the doctor made two things every clear. That I would have to take the medicines by the clock and that too after I had eaten something. He said he would keep the stronger pill for the evening so that the side effects, if any, would not hamper my work. Now I get up in the morning and have a biscuit or a handful of grams and then pop a pill. It doesn’t wear me out. Then I go to work (she still works as a domestic help). The evening pill is a problem because it still makes my head spin. But now the doctor and the FCM have helped me find a way around it. I eat my dinner by six in the evening, have the pill and immediately go off to sleep. You can say my life is from dawn to six, but now it is a good life. I have worked my way around those pills.”

Ramja Bi’s is not the only one who benefitted from intensive counselling. Across all Balasahyoga regions there are instances of people responding because of counselling.

Sister Love

Venkatalakshmi a PLHIV (Person Living with HIV) , in Anantpur, lost her husband to the virus. HIV still brings in its wake severe discrimination; Venkatalakshmi was no exception. She had two young children to bring up but did not feel confident about being able to do so.

When the Balasahyoga FCM met her, she realised that Venkatalakshmi's sister Lakshmi Devi and brother in law Chinnaramadu lived next door. The sisters were married to brothers and therefore bonds ran deep. She rightly assessed that they could become the all-important psychosocial pillar of support for Venkatalakshmi, if they were counselled properly.

She approached the couple and spoke to them about HIV and the need for a supportive environment for PLHIV. Most importantly she wisely roped in the couple's 13 years old daughter: the bright and articulate Akhila.

As Lakshmi Devi says:

“ She's my sister and her husband was my husband's brother. So in some ways my husband also felt responsible. But we were terrified of the virus. We did not know what it could do and what it couldn't. We have a young girl Akhila who is about 13, we needed to think about her too. The first few days were pure hell for us. But then they(pointing to the FCM and Akhila) helped us understand and cope with the disease.”

Chinnaramadu looks at his daughter proudly:

“ She's in class eight and knows about HIV. She told us that it is not contagious and that with proper medication and good food a person can live for years. Balasahyoga Madam also told us how it spreads. Now I have no fear. Venkatalakshmi is our sister and we will look after her and her children for as long as it takes.”

The couple have now not just become a pillar of support for the frail Venkatalakshmi but also a deterrent against further discrimination. A supportive family acts as a protective barrier and discourages people from being judgemental. It also acts as an eye opener, communicating the fact that one can live with a PLHIV as with any other person.

As we leave, Akhila hands over a steaming cup of tea to Venkatalakshmi. Aunt and niece sit cross-legged on the floor with the easy camaraderie and talk in soft tones. As the sun starts to dip, the tea once again becomes a metaphor for shared warmth.

