

INTERVIEW: TSETEN LEPCHA

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"The News of Cancer is one of the most shattering Experiences in a Person's Life and it was the same with me"

Intro: Tseten Lepcha, a founder-member and working president of the Affected Citizens of Teesta and also included as a member of the Plenary Board of the World Mountain People's Association which has taken up the issue of hydel projects and climate change with the UN, speaks to NOW! about his continuing battles – against Cancer and hydel projects, and also addresses his involvement in the steering committee for the implementation of Teesta Stage-III ...



"Since the Movement (ACT) managed to groom many young Persons, my own Role is not so important"

NOW: You have been keeping unwell for a while now; your well wishers would be keen on an update. Could you share what has kept you out of circulation for the past few months?

TSETEN LEPCHA: Thanks for your concern. Yes, due to various reasons, I have been out of circulation for some time now. The primary reason has been due to issues concerning my health. The initial problem started last year when I had to undergo an appendix operation, due to which I was advised to stay away from strenuous activities for some time. Then, the devastating 18th September Earthquake destroyed my village (Chungthang) and confined me there for months and all my energy was focused on providing relief, restoring essential services and rebuilding the devastated area. Since the earthquake wrecked complete chaos on our lives and we were constantly running around to rebuild the lives of the affected people, health issues took a back seat and it was only after an incidental checkup that I was informed of worst possible problem - a tumor in the left kidney was suspected to be cancerous.

After a series of tests and consultations, the tumor was removed at the Rajiv Gandhi Cancer Institute & Research Centre, New Delhi on the 19th of March. Since then, I have been more or less confined indoors and of course preparing for the 3-month deadline when I will have to go for review to see if the cancer has resurfaced and if it comes back,

will have to start everything all over again and in case it doesn't, then get time till the next checkup which will be after another three months.

NOW: Cancer has grown into a major health concern in Sikkim. Unfortunately, it is also very little understood. Did you and your family also confront confusion and fear when you were first diagnosed? How, if you did, did you overcome the anxiety?

TSETEN LEPCHA: Cancer has definitely grown in to major health issue, particularly for people of North Sikkim. In recent years, we have witnessed unexpected growth in the number of Cancer cases and numerous deaths. The news of cancer is one of the most shattering experiences in a person's life and it was same with me; the only difference was that I knew it before my family members and so had shared the news gradually with them, lessening the impact. The lack of general awareness regarding cancer is a major problem, but since I was in New Delhi with a lot medical options and moreover internet provided a lot of valuable information as well. Handling the initial shock was relatively easy, but taking a decision in such situations is difficult. I had two options - one being radical nephrology (taking out the kidney) which reduces chances of the disease spreading or seeking other alternatives like the one I opted for, going in for surgery to remove only the tumor with the chances of reoccurrence of the disease. Whether the decision was right or wrong only time will tell.

As far as anxiety and the trauma are concerned, the first challenge is to accept the fact that you have the most dreaded disease and that there is every chance of fatality. Since cancer is a freak case not necessarily brought on due to an unhealthy lifestyle, we took it as our own Karma and accepted to face the consequences. We have no illusion that I will be the one who can survive cancer, in that sense we are prepared for the worst, and yet, at the same time moving ahead with positive expectations.

NOW: Could you also walk us through the medical procedure from the diagnosis to the path of recovery? How difficult is the process?

TSETEN LEPCHA: Initially it was detected as a cyst/ tumor in ultrasound and since the growth was suspicious, an ultrasound contrast was done by injecting a fluid in the body, then further blood tests, chest x-rays, kidney function tests, CT scan, ECG & ECO cardiogram etc followed. These tests more or less confirmed that the growth was cancerous. The doctors at Sir Ganga Ram Hospital (New Delhi) advised me that the best option was to remove the kidney as it rules out any chances of the disease spreading and since priority was to contain it, we wanted to opt for it but the test also showed presence of small calculus (stone) in the right kidney which posed a problem. After completing all pre-surgery tests and formalities for admission, I broke the news to my friends and they, one after another, refrained me from taking a drastic step and insisted that I take other opinions and options.

Thereafter, I went to AIIMS and managed to get an appointment with the urologist, but due to the massive crowd, it was practically impossible to get any treatment done in short period and since time was crucial, we went to Rajiv Gandhi Cancer Institute, also in Delhi. Fortunately, being an OPD day, all the senior specialists were present, including the Head of Department of Urology. After examining my reports the Doctor said that the best option under the circumstance was to go for Left Robotic Nephron Sparing Surgery / Partial Radical Nephrectomy. He further assured me that there won't be any need of chemotherapy as the disease was more or less in early stage. The final treatment process

would be followed after the (histological) Biopsy report. Since this option was much better, we took it and with support of the family, well wishers and the IRB Personnel from Sikkim stationed in New Delhi who donated much-needed blood, the surgery was done within two days and I was discharged after seven days.

The Biopsy report confirmed that it was conventional Renal carcinoma, clear cell type furhman Nuclear Grade-II (cancer) but localized and had not spread. As a further confirmation a bone scan was done which fortunately came in negative. After that I was told to report after every three months and since then having treatment to flush out the stones to make the right kidney in proper working condition in the event that I have to remove the infected one.

The most difficult part of the treatment is the time in the ICU, with numerous tubes and monitoring equipment attached to the body. Moreover, this is the most trying time for the family as they have to wait outside for days on end. It is while in the ICU with Ryles Tube in my nose that I wondered how Irom Sharmila of Manipur must be enduring it. I also wondered how our own ACT members, Dawa, Tenzing, Ongchu and Tashi Namgyal must have spent so many days under such, most frustrating and helpless conditions. It gave me the strength to get over it as I was in much better condition with doctors everywhere.

NOW: Since there are so many Cancer cases in Sikkim nowadays, drawing from your own experience, do you think there is need for a fresh policy initiative in the healthcare system here to assist patients better?

TSETEN LEPCHA: Honestly, I am just starting to understand the situation in Sikkim and found out that there is actually nothing much in form of support for private individuals except for some monetary support not exceeding Rs 50,000. I wish a campaign was launched like the one done for HIV/ AIDS and other diseases so that the people could be better prepared; moreover, since the treatment of cancer and other critical illness is a very long drawn and expensive affair, I wish that govt could provide more financial and logistic support on priority.

NOW: Since you have gone through the entire process yourself, what would be your advice to other patients with similar diagnosis and for their families as well?

TSETEN LEPCHA: Through my own experience I found that the most essential step is to have timely medical checkup for all ages. The best thing about early detection of any ailment is that the condition of the person is not totally inflicted and treatment is much easier, particularly if one has to go to big cities, being bedridden and then going through the process in hot and humid conditions is not only frustrating but torturous both for the patient and the family.

Further, it is very important to be health conscious and maintain good physical condition by exercising and maintaining a healthy balanced diet. A healthy person is much easier to operate on as all other vital parameters are functioning well and recovery is also much faster and less stressful. Personally, I feel restricting consumption of alcohol, smoking and chewing of tobacco etc, though it may deprive some fun from life, proves a major factor in combating serious diseases. The feel-good factor is an added incentive.

As far as my personal opinion or advice to other person inflicted with cancer or other critical illness is concerned, it is very important to accept the fact that something serious

has happened, secondly share it with family, relatives and well wishers. Once others know about the problem, lot of support comes in various forms like medical advice, logistics, financial support etc. It is critical to take the right decision after due consultations and considerations.

Further, do not shy away from asking for help, there are good and generous people who will help, of course, one should not forget about it even if we cannot repay the same.

NOW: You are also actively involved in the hydel protest through ACT and also overseeing the implementation of conditions imposed on Teesta Stage-III as part of the monitoring committee in Chungthang. How has the illness impacted your involvement in these issues?

TSETEN LEPCHA: Being a founder-member of Affected Citizens of Teesta, we are happy that we managed to launch the most vibrant and long drawn civil society movement in the History of Sikkim. Though the struggle is far from over and is rather an unfinished or unrealized Agenda. The fact that we awakened the consciousness of the Sikkimese people and managed to scrap four projects in Dzongu has been our biggest achievement. It does give us lot of satisfaction when we see people from all walks of life from different communities and backgrounds now being involved and raising their voices against destructive projects in the State. The recent boycott call of the Public Hearing of Teesta HEP Stage IV by the Government is also a positive sign and vindication of our stand, not forgetting the scrapping of two projects in west Sikkim.

Since the movement managed to groom many young persons, my own role is now not so important.

Further, my role as the President of the Steering committee for Teesta III is equally challenging and requires lot of effort, there are many issues that have not been resolved, and since it entails my presence in the field, it will be difficult for me to carry on like before. There is no doubt, this illness has certainly affected my functioning capacity and I have hence requested the younger generation in ACT and the Steering committee to take over the responsibilities.

NOW: Going back to your involvement with the monitoring committee for Stage III, many would see this as being in conflict with your stand against hydel projects as espoused by ACT. How do you explain this?

TSETEN LEPCHA: As far as my involvement in the steering committee for implementation of Teesta HEP Stage III (Damsite) is concerned, it all started after a large number of people of Chungthang requested me and our organization to help them fight against the ill treatment that they were facing. It was brought to our notice that most of the promises made by the company and the Government while taking the land were not complied with, there was total lack of transparency in awarding works, blasting was rampant, the locals were denied their right to work, the relief and rehabilitations was in chaos as it was managed by an NGO of the implementing Company itself. Over all, instead of Teesta Stage III being a developmental project it more or less became a way of creating more problems for the people.

Since, it was my native village, and hailing from a family that has been traditionally leading the people, it was also a call from the very people who during our school days parted with the little money they had to give to us, not forgetting the whatever grains or

livestock that they presented to us, expecting us to study well and since it was the time when these people needed us the most, as an informed citizens as well as an activist I had to accept the new role. It was very difficult to shy away from the responsibilities even if it was going to differ from my normal path.

There is no doubt that it was a very difficult decision not because it was in conflict of my role as a social activist but more so because of the perception of the people. Though it is my own personal opinion that everyone has the right to their perception and we have to face the consequences of positive and negative reactions. It is also a fact that the society is sometimes unfair and passes judgment without understanding the real issue and the constraint that someone has to face. There is also a problem in approach to dealing with issues; for many persons, the means is considered more important than the end, if anyone explores different ways to achieve the target, very often it is viewed with suspicion thus creating distrust and obstacles in functioning of the organization and as a result many important issues don't get resolved and people keep on getting exploited and suffer.

Further, the expectations and the qualification of being an activist are sometimes not only unrealistic but absurd. If anyone speaks of corruption then that person has to be like Anna Hazare, if one speaks of hydro project and environment one has to be like Medha Patkar so on and so forth ...

The activists are expected to always live frugally, travel in third class train compartment, stay only in dharamsalas, eat only in dhabas, never fall sick, never take up any trade and possibly be without any family commitments but have to keep on fighting the Government, administration and the corporate world.

Another serious conflict in the stand that a civil society group takes vis-à-vis issues relating to Hydro Project or any other project is that if one opposes the implementation of the Project and in the event that it cannot be stopped and is implemented. Then we abandon the entire issues and never make any effort to see what is really happening like in case of Teesta HEP stage V and other projects, where, due to lack of organized monitoring the people are deprived of their rights and are facing a lot of hardships. Normally, as a standard operating procedure we are supposed to stay away or else be seen as compromising and having sold out. However, I believe, we have to look at things beyond one's own image; the larger issue of protecting our people and the environment cannot be totally discarded. If we do, we neglect the very issue for which we stand for. The issue of Teesta HEP stage-III was a classic case and needed intervention.

So, in the backdrop of such perceptions, I did lot of discussion with my friends and experts. It was collectively felt that it was very important for us to introspect, review and reinvent our own role and usefulness for a cause. It was also important to asses our effectiveness in combating not only the Government agencies but the enormously affluent corporate world. It needed a paradigm shift from the old approach to a new way and finally, it was with unanimous consent that I took up the cause of the people even if it appeared to be in conflict with our normal approach.

Then, after a meeting was held in the GPU and as per the wishes of the people, a Steering Committee was formed to monitor the implementation of the Project at the Stage-III damsite. However, we decided that none of the Members of the steering committee or their immediate family members should take up any contract or other work under the project.

Since then we have been able to bring to focus the rights of the indigenous people and now everyone in the project area is a legitimate stakeholder and their rights protected. If not anything else, then at least the dignity of the Sikkimese people was restored. A large number of the conditions have been complied though there is still a lot to be done. Further, the process of distribution of works has been streamlined and far as possible everyone was given a share of it. Many complicated pending issues relating to land compensation, employment and social impact issues were resolved.

However, since the Govt did not have any provisions in the MoU to provide protection in terms of socio-political-economic rights of the affected people, the benefits to the people are largely reduced.