

# **BE POSITIVE**

*“With HIV it can’t be done quietly. You have to be loud you have to be vocal, because at the end of the day this is about sex and drugs.”*

*Josh Levinson*

## **FOREWORD**

**We have the voices, which are loud and clear when they talk about HIV, and Be Positive is an effort to give a concrete shape to these voices.**

**Listening to these voices is a pre-requisite for the management of HIV because the infection is not related to a person’s health alone. HIV is an issue having strong links with the social, cultural, political and economic fabric of society.**

**Despite rising knowledge and awareness levels, stigma, discrimination and embarrassment are closely associated with HIV/AIDS. The infection continues to be linked to sexual behaviour, and a person’s character comes under scrutiny the moment their status turns positive.**

**Many misconceptions and misinformation about HIV exist even today. Conversation about sex and sexuality is considered a taboo in almost all the societies, even in the most advanced ones. The advertisements are often quite scary and the literature too technical for common man to comprehend. As a result, this situation makes the young generation one of the most vulnerable populations to HIV.**

**Since knowledge can help us win over the terror of infection the need is to inform people about the ways the infection is spread and educate them about the treatment available.**

**Be Positive narrates the stories of positive people who accepted their status with courage and dignity and decided to live their lives with their heads held high. The stories of their life experiences educate, inspire, motivate, and serve as examples to others like them, across generations.**

## **ACKNOWLEDGEMENT**

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**The UN agencies have a major role to play in the creation of this useful knowledge bank, which does not talk of statistics or technicalities of HIV but presents a human face of the infection.**

**The documentation team got full support of the Ministry of Health and its national consultant Dechen Wangmo, who ensured that Be Positive sees the light of the day with a positive note and sends across the positive message—‘together we can do’.**

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## **List of Abbreviations**

<b>AIDS</b>	<b>Acquired Immunodeficiency Syndrome</b>
<b>ART</b>	<b>Anti-Retroviral Therapy</b>
<b>CSOFF</b>	<b>Civil Society Organisation Fund Facility</b>
<b>HIV</b>	<b>Human Immunodeficiency Virus</b>
<b>IDU</b>	<b>Injecting Drug Users</b>
<b>IPPF</b>	<b>International Planned Parenthood Federation</b>
<b>LSE</b>	<b>Life Skills Education</b>
<b>NACP</b>	<b>National AIDS Control Programme</b>
<b>PLHIV</b>	<b>People Living with HIV</b>
<b>PMTCT</b>	<b>Prevention of Mother to Child Transmission</b>
<b>RENEW</b>	<b>Respect Educate Nurture Empower Women</b>
<b>STI</b>	<b>Sexually Transmitted Infection</b>
<b>UNDP</b>	<b>United Nations Development Programme</b>
<b>UNAIDS</b>	<b>Joint United Nations Programme on HIV/AIDS</b>
<b>UNFPA</b>	<b>United Nations Population Fund</b>
<b>UNICEF</b>	<b>United Nations Children's Fund</b>
<b>VCT</b>	<b>Voluntary Counselling and Testing</b>
<b>WHO</b>	<b>World Health Organisation</b>

## **INTRODUCTION**

### **BHUTAN**

#### **A NATION STRESSING ON GROSS NATIONAL HAPPINESS**

*“The health of the people is really the foundation upon which all their happiness and all their powers as a state depend.” Benjamin Disraeli.*

Bhutan grasped the essence of the saying and became the only nation in the world, which weighs and judges its growth and development through Gross National Happiness (GNH) instead of Gross Domestic Product (GDP). The country has put people’s happiness on top of its monetary gains. The philosophy of Gross National Happiness upholds strong principles of equality for all human beings with regard to their rights and responsibilities.

The country became a democratic constitutional monarchy in 2008. The Wangchuk dynasty carefully nurtured the nation into the path of modernisation whilst preserving its unique culture and traditions.

Bhutan is a landlocked nation bordered by China in the north and India on the south. The country has the lowest population density (12 persons per square kilometres) in South Asia. Characterised by a high fertility rate and a declining mortality, the nation is leading to a rapid population growth.

Despite this population growth, which is combined with tough geographical terrains, limited human resources and financial challenges, the country has been able to maintain impressive healthcare facilities. Overall 90 per cent of the population has access to basic healthcare services and the immunisation coverage is also 90 per cent.

Striving to become a healthy nation in order to achieve its motto of Gross National Happiness, today Bhutan is focusing on HIV/AIDS. The target is zero new HIV infection by 2015. The government of Bhutan has realised how serious is the social and economic impact of HIV infection on the individual, family, community and ultimately on the state.

## CHAPTER ONE

### POSITIVE VOICES

***“I am not afraid of tomorrow, for I have seen yesterday and I love today.”***

- ***William Allen White***

These simple words uttered by a renowned journalist, author, politician and the leader of the Progressive Movement in the United States, underline the courage, determination and strong will of people whose life stories have been narrated in this book.

They are young and creative. They had been living normal happy lives bubbling with joy before one fine morning a simple blood test changed their status. From negative, they became positive. For a moment life lost all meaning to them.

A bit of struggle with their internal world and the external surroundings, and they finally emerged winners. Their positive attitude overpowered their positive blood. They stood up to embrace their lives with fresh vigour.

They have been witness to various shades of life—from vibrant hues to shades of grey. They could either succumb to fear and weakness or fight back. What they were left was a bright hope and a strong will to look forward and reclaim their lives, and they did it. Today they stand strong and beautiful as inspiration to many others while they narrate their stories to be shared with the world.

*NOTE: A few of the story narrations mention the real names of people, which have been used with their consent. Other narrations carry fictitious names to protect their identity. Any resemblance to actual persons, incidents or situations is purely coincidental.*

## **(1) The joke that changed her life:**

After donating blood for the colleague who was admitted in the hospital Chong Kinley [fictitious name] came back to her office and jokingly told her colleagues, "I have donated my blood but that's a waste. I am HIV positive!"

Two days later, she got a call from the Public Health Officer. He asked her for another blood screening as the first report was not clear. Chong went to see the officer, who gently asked her, "What if I tell you that you are HIV positive?"

The question was straight and it made its impact.

"I was numb. Although I had always feared of having caught the infection by the man I lost my virginity to, there was part of me which said nothing would happen to me. Therefore, when I was tested positive the news came to me as a shock."

After breaking the news, the officer was now talking to her, asking questions like what she knew about the infection, CD4 count, treatment etc. Though physically present before the health officer, Chong's mind had wandered to a different time zone. Nothing was actually getting registered in her brain.

"At that moment I was only thinking about my aunt, who was waiting outside for me. I did not want her to start getting ideas if I took unusually long to come out."

The year was 2006.

A giggly young girl, Chong normally jokes about everything. Her wholehearted laughter is infectious. But that day she was unusually quiet. The family went for a picnic the next day and there she had a fight with the park caretaker, an unusual occurrence for Chong. She skipped office on Monday on an excuse that she was having heavy menstruation and a bad backache.

There was turbulence inside her, for she was unable to share the burden of that heavy news with anyone. The best way out was to run away from it.

"I did not want to see the counsellor. Every time he called me I either switched off my phone or put it on silent."

Gradually the reality sank in and Chong resumed her normal life. For four years she carried on without sharing with anyone the secret embedded deep in her heart.

One day she fell ill. That was the time Chong confided in her youngest sister among her five siblings. Her sister accepted it with a mature understanding and kept the news a secret.

“My parents are uneducated. For them HIV is a sexually transmitted disease, which infects only sex workers. They would not be able to take it that their own daughter is HIV positive. But that does not mean I will never tell them. I have plans to reveal my status to them after my two elder brothers are settled”, says Chong.

Sharing her life’s journey, the bubbly girl Chong (now 26 year old) recalls that past incident, which created doubts in her to have got infected by the virus. “After a week of having physical contact with my first boy friend, I was diagnosed with a Sexually Transmitted Infection (STI). When the doctor asked me if I had had sex with someone, I declined. I was only 18 then. But I had misgivings as that man was casual about sex, used to visit Bangkok frequently and we did not use any protection. Despite my doubts, there was a wishful thinking that I might not have contracted the infection as we were together only once.”

She was not a sexually active girl.

It was hard for Chong to believe that a bluff played by her would have such serious implications in her own life. It took time for the jovial girl to get back to her life and laughter. What helped her most was a meeting with other positive people in 2009. The meeting changed her life. Now she goes to the health centre for regular check-ups and to collect medicines. Her job is carrying on well.

Chong is also keenly involved in indirect advocacy, since her colleagues and friends are not aware of her status. “I continuously keep talking with my friends about HIV infection and persuade them to practice safe sex. Sometimes they question as to why I always talk of HIV. I jokingly tell them that I am HIV positive and that’s the reason I talk about it.”

Moving on with life, and on advice of her sister, Chong is mulling over the idea of adopting a child now, and making her life complete.

## **(2) Her Past made her Future Perfect:**

Under the influence of drugs, Chempasaro Dema (fictitious name) was amazing on drums. She could also strum pretty well. Deep into hard rock

music, she was always out with friends, living life dangerously. They shared music, laughter, ecstasy and also syringes!

The inevitable happened and she was detected HIV positive. By the time the truth hit her she had already withered her life away. Chempasaro was only 19.

Bhutan has less than one per cent cases of HIV transmission through blood transfusion or by injecting drugs.

The story dates back to the time when Chempasaro was 14, studying in class six. It started with beer, which she and her friends consumed to enhance the fun element in life. The low alcohol percentage drink was soon replaced by hard liquor, and before these adolescents could realise what they were in for, chemicals had made their way in. Ten years on, Chempasaro was injecting drugs into her weak and delicate body.

Losing control over their daughter, Chempasaro's father and step mother threw her out of the house, which made things worse for the young girl wasting away her life.

She passed class 12, got married and delivered a premature baby in seventh month of pregnancy. The baby weighed less than a kilo. The husband not ready to share the responsibility, left her. Chempasaro started living with her twin sister but she too could not take it for long and asked Chempasaro to find another place to live in.

Life carried on for a decade without Chempasaro realising what was happening with her.

"I had 15-16 over doses of drugs. Prison had become a second home for me, which I liked sometimes as there was no other place to live. I was sleeping on the roads, in front of shops or wherever I would pass out. I had left my child with my sister as I had no money and no place. There were no friends left and the family had already abandoned me. Still, there were some well wishers left, who sent me to Alcoholic Anonymous and Narcotics Anonymous groups but nothing helped me. I had hit the rock bottom, from where it was either prison or death waiting for me. I thought since I am dying it's better to speed up the process. I started injecting double doses."

A 26-27 year old woman, Chempasaro weighed only 30 kilos and was slowly withering away.

Even when a person loses everything, the one thing that remains is hope. This hope led the young girl to a self-realisation—a wish to survive. That wish dragged her to a rehabilitation centre. But there was no money to pay

the fee for the centre. It was then that RENEW (Respect Educate Nurture Empower Women)—a crisis management centre for women in distress—came forward to give her a new life.

The rehabilitation centre does the blood screening of each new entrant and before the screening the entrants are also inquired about the substance (narcotics) they have been consuming. When Chempasaro's revealed her high risk behaviour, the counsellor at the centre also advised her to go for HIV testing. The result was on the expected lines. She had tested positive.

"I knew it as we used to share syringes. Also, look at my tattoos... (she says showing her tattoos) I have so many of them. We used just one needle amongst us to get these tattoos."

Narrating the horrifying experiences of her life Chempasaro's face showed no signs of guilt or regret. Her strong jaw line and sparkling eyes reflected a firm determination for a restart.

"After revealing my status, the sister at the rehab asked me to go in the other room. She said 'cry, scream, shout and come back then we will talk'. I went to the other room but there were no tears. I knew I had to reap what I sowed. That was the time I got rather clear and positive thoughts. For the first time I was looking forward in life without any drugs. The only person I shared the information with was my twin sister. She calmly said 'I knew it would happen, Chempasaro.'"

The rehab did wonders to Chempasaro who started living a new life after that. "The positive status gave me a positive outlook in life. Earlier there was nothing to look forward to but ever since after I tested positive I have looked forward to life."

Today she works as a counsellor at a rehabilitation centre and teaches others from her own experience. Regular check-ups and stringent schedule of medication are keeping her fit.

The only worry Chempasaro has is to protect her son (who is growing into a fine gentleman) from falling prey to drugs, since he has the genes of an addict mother.

"I pray to God that he does not fall prey to this risky behaviour. Now every minute and every second of my life is important to me. I want to do all those things, which I always wanted to but could not do. The most important thing for me is to prepare my son for life's journey. If I accomplish that, I will be happy and then I would not mind ending up in a day care centre."

### **(3) Wish there was a counsellor!**

In the early 90s, very few people in Bhutan knew about the HIV infection and even those, who did know about it, could not differentiate between HIV and AIDS. There was no counselling and no adherence of confidentiality. Who would know the situation better than Namgay Lhendup, a non-commissioned officer in the Royal Bhutan Army.

Namgay Lhendup was sent to Allahabad in India, in 1994 for a training course in nursing. As per the rules, blood screening is done of all those going for inter-country training programmes. Namgay gave his blood sample and proceeded to Allahabad.

Two weeks later he received a telegram—"wife critical, come back immediately".

Namgay returned but found his wife to be perfectly fine. He reported to Head Quarters, where the officer on duty casually told him that he was HIV positive and hence could not continue with the training.

"The news was direct and came as a shock to me. I had no idea what HIV was. My knowledge was limited to what was shown in advertisements, which said HIV/AIDS is dangerous. I thought I would die within 2-3 months."

The news of impending death had already killed Namgay, more so because he could not share it with anyone. He drowned himself in alcohol. "Alcohol did not help but it did make me sleep for a few hours."

Three years later in 1997, the same officer who had given the death sentence to Namgay by telling him his status, broke the news to his wife. An understanding woman, she cried only for a while and soon after accepted the fact. The counsellor persuaded her also to go for a test. She tested negative.

But destiny had other plans. During her pregnancy in 2003 she was tested positive. Unlike Namgay, who had started mourning his death the moment her test result was out, his wife reacted wisely and bravely.

She told Namgay, "Everyone in this world has to die one day. We will also die, so why worry so much!"

The wise words had their impact, but by the time Namgay came to terms with his status, he fell ill. The same officer examined him, and this time he shared the news with everyone in the office.

Due to lack of knowledge and scary Information, Education and Communication (IEC) in the early 2000, people could not differentiate

between HIV and AIDS, and Namgay's colleagues started referring to him as 'the AIDS patient who would die soon'.

"I stopped meeting people. When my wife went out for some work people whispered behind her back. We had a very difficult time facing stigma and discrimination."

Even very recently at his son's school, Namgay's son was standing in a queue for a routine blood test. The wife of the same medical officer from Namgay's office, who had detected the virus in Namgay and his wife, was teaching in the school. When Namgay's son's turn came, she said 'there is no need to test this boy. His parents are positive and he has to be positive'.

Namgay has four children and all are HIV negative.

"That one sentence changed my son's life. Three times we have changed his school. Now I have sent him to a school in the eastern region where no one is aware about our status."

Now, with increased knowledge and better medical facilities, Namgay and his wife are living a normal life. But the credit for this goes to a PLHIV meeting conducted by the Ministry of Health in 2009. A lot of sharing was done in that meeting, in which positive persons realised that they are not the only ones, but there are many others living similar lives.

"The feeling that I am not the only one was very encouraging. Now I joke with my friends and colleagues about my status. They call me 'the HIV patient', but there is no discrimination. I also joke with them and tell them that I am ready to donate my blood if there is anyone needing blood anytime. They laugh."

Today, Namgay has no complaints with life. But there is one wish that remains unfulfilled.

"I wish there were counsellors at that time. If someone had told me about the dynamics of the virus, I would have lived a cautious life. I would not have consumed alcohol and I would not have fallen sick! Most importantly, I would not have transmitted the infection to my wife!!"

#### **(4) For people I was dead**

How does it feel when people are reluctant to stand next to you or sit on the same chair used by you a minute before? Ask 42 year old Pema Dorji and he would explain.

In 2001 Pema's first wife was expecting their second child. There was no Prevention of Mother to Child Transmission (PMTCT) tests in Bhutan in 2001. The test came in force in 2006 when the Ministry of Health issued national guidelines for PMTCT and paediatric treatment, which were included in the HIV care and treatment guidelines.

Pema and his wife went for routine blood tests and were tested HIV positive. Without any pre or post-test counselling, the health officer coldly told the couple, "You can survive for ten years if you take precautions."

The couple was obviously shaken and decided to keep it a secret. But one evening, the wife, in an inebriated state, shared their secret with everyone sitting in the bar at that time. Within no time the news spread. The wife was the first one to desert Pema.

"My sisters told my father that an HIV patient should not be kept at home as he might infect others. My father threw me out. I went to live in my ancestral home in another district. But one day, when I came back from office, I saw my stuff thrown outside the house. I was completely broken. I thought that even though I was not dead, I was being treated like one. Even the doctors would wear gloves and masks before touching me, even if I went to them complaining of chest pain."

The situation in office was not very encouraging either. No one would sit on the chair used by Pema. His colleagues tried to maintain a physical distance from him. He was aloof and alone. No family. No friends. He tried getting some support from Ministry of Health but efforts were in vain.

Death was the only alternative Pema could think of to end his miseries and he bought some rat poison. "The poison did not work, may be my time hadn't come. I decided to attempt again by hanging myself from the fan. Before executing my idea, I decided to talk one last time to the health officer who had told me my status and changed my life."

Pema called the health officer in the middle of the night and told him that he felt miserable as there was no support or no help in sight and life seemed useless. The health officer asked Pema to hold his idea and think about it for just two days.

Those two days were enough to give Pema an insight. He realized that things would not change if he stayed in the district he was in and kept brooding.

He confided in his boss about his status and the effect it was having on him, and sought a transfer to the capital.

“When leaving the village I also left behind all the frustration and stigma I was carrying. I told myself that it is only my body that has got infected, not my brain or my heart. I decided to start a new life.”

## **(5) Ignorance is bliss**

What Pema brought along with him to the city was hope for future and a girl still in her early teens, Sonam Yangden, who had looked after Pema in the village. Sonam knew of Pema’s positive status and had no problems with that. “I didn’t know that there was any danger in having HIV infection.”

But Pema was aware of the dangers and wanted to protect Sonam. They always had safe sex. On one of the occasions, the condom tore. Pema frantically called the health officer who asked him to get Sonam’s blood tested after three months. Sonam tested positive but the news had no effect on Sonam, who had no idea what HIV was.

Life resumed but destiny had some other plans for the couple. The condom mishap was repeated and Sonam became pregnant. “This got me a bit worried. I did not want my child to have any problems. But I didn’t know what to ask the doctor so I left everything to Pema and let him decide.”

Sonam was given medicines, which restrict mother to child transmission by 90 per cent. The child has undergone two tests so far and has tested negative.

Both Sonam and Pema revealed their status before the media in December 2011. Today they are engaged in active advocacy programmes. Pema, who is fond of cycling, pedals at least five kilometres every day. “It helps me reach more and more people and is good for my health as well. Besides, the treatment has become so good that it helps us live normal lives,” says Pema.

A bold and carefree girl, Sonam is 21 year old today and she feels that all HIV positive people should come out and get involved in advocacy.

“Before revealing my status to the media, I was a bit concerned about how people would take the news. But then I thought it would inspire others to go for voluntary testing—especially pregnant women—to save their unborn babies from getting the infection. Also, this is the only way we can stop discrimination.”

## **(6) Positive makes you selfless**

In Bhutan, 90 per cent of HIV transmission is through heterosexual intercourse, followed by mother to child transmission which is 9.2 per cent.

Karma Yangky (name changed) knew that it was she who had infected her partner Jigme (name changed). She came to know about her status when she went for the mandatory blood screening during her pregnancy in 2007. She was 25 then and PMTCT test had become mandatory in Bhutan for all pregnant mothers.

“I was in a turmoil, weighing whether I should tell my husband or not. Then I thought I cannot live with such an important aspect of my life hidden from him. Besides, the counsellor had asked me to get his blood tested as well.”

Jigme was tested positive. The couple was shell-shocked for a moment before the agony gave way to tears. Initially, Jigme could not take the news. “I felt discouraged and angry—I was angry with God and angry with my partner, whom I slept with. I thought my life was now over.”

The couple kept the news to themselves but the self-stigma made them leave their jobs. People’s gaze pierced through their bones. They thought everyone knew about their status. Both Karma and Jigme went into their shells with no friends and no acquaintances around. Eventually, they left the big town and moved in with Jigme’s family in a small village where no one knew their history and their son was also taken care of.

“Jigme’s mother would insist that I breastfeed my baby. Sometimes she would sarcastically say, ‘what kind of mother are you, who do not want to feed the child!’ I told her that I was suffering from a very bad form of breast cancer and there was no milk in my breasts. His mother would make local wine for me, which is given to lactating mothers in Bhutan to increase milk.”

As days passed by, an invisible divide was created between Karma and Jigme, which grew deeper without their realisation. Jigme started consuming alcohol and spent more and more time with friends. His behaviour was becoming wilder and increasingly more uncaring towards Karma. Their fights had become a routine feature in the house.

Karma, on the other hand, racked with guilt, couldn’t fathom if Jigme wanted to stay with her anymore.

The situation led to a major confrontation between Karma’s and Jigme’s families—both ignorant of their children’s status. One day Karma’s family

arrived at Jigme's house and heated arguments ensued between the two families. In the middle of the arguments, Jigme shouted—"Why are you all fighting so much. There is no need to bother, as both of us are HIV positive and are going to die soon."

The bomb thrown by Jigme had an impact. Initially, it caused a deafening silence and then suddenly everyone was talking of their children's happiness.

"Both our parents thought we would be living for a very short time now and they wanted us to live with them so that we could spend more time with them." Karma

With mutual consent of the families, Karma and Jigme were separated and started living with their parents. Their son stayed with Jigme's mother who had been looking after him.

For a year they stayed away from each other, before realising that they could make a life and be happy only if they were together. A mutual friend got Karma's phone number for Jigme, who started calling her.

"One day he just walked into my mum's house and told me that our son was happy and healthy and was missing his mum. I couldn't control my tears," Karma recalls.

Once again the couple was together—this time wiser, more mature and closer to each other.

"In 2009 we got an opportunity to attend a meeting of the PLHIV. The meeting was organised by the Ministry of Health. We got a chance to meet others like us. It was such an overwhelming moment for us to see that we were not the only HIV positive people but there were many others and they were living normal lives. We felt inspired and alive again," says Jigme.

The meeting infused a new life into Karma and Jigme. Soon after, the couple was chosen for a study tour of PLHIV to Bangkok, where they met Wangda Dorji, who later became the Executive Director of Lhak-Sam, the Bhutanese network of positive people.

"There we met many people who were living with HIV, and who had no problem in accepting the fact and telling people about their status. Until that time we had no idea about treatment. We came back not only informed but also enthused to work for others like us. I instantly decided that I wanted to become a role model for others," says Karma who is now an advocacy trainer and is associated with Lhak-Sam.

She is also invited at programmes to share her experiences. She knows how to deal with HIV and educates others with her experience and knowledge.

“Life is beautiful when we know what we want to do and we can do it. I have no guilt and no complaints. The only regret I have in my life is that I could not breastfeed my child because of my physical state.”

Jigme has no regrets. Today he is happy that he is positive because he feels that a positive person is selfless. “I thank God for making me positive. It has given me a chance to help others. I would have thought only of myself had I not been detected positive.”

Karma and Jigme make a beautiful couple. Today they do not want to blame each other for their status but stand together as each other’s support. Jigme has reconciled with his past. “Look at my tattoos, I have many of them. Then I also had a playboy nature. Both could have been the reason for my status”, he says.

Both Karma and Jigme are healthy and happy. Their son has tested negative and is growing into a lovable child under the guidance of his dotting parents.

## **(7) The jail rock**

It required lot of courage for 34 year old Wangda Dorji to invite the media representatives to share his positive story with them. There were apprehensions in everyone’s mind as to how the world would take it.

The reactions were startling! A lady in Wangda’s village, whom he had never met, became so upset that she did not touch food for two days. Some of his friends got angry because they got this important information through media. The brothers started taking away any burdens he had and pushed towards him all that was nutritious and healthy.

Wangda’s mother was so overwhelmed that she could not stop tears rolling down her eyes although his father did not believe the news. He called Wangda and asked, “There are many rumours about you in the village.” Wangda calmly told his father that whatever he had heard was all true but he did not need to worry as now there was treatment available for AIDS infection.

In his childhood Wangda had a dream to become an administrative officer or engineer, but wrong company shifted his focus from studies to drugs. Soon he was injecting drugs, even in front of his wife, who was 12 years younger

to him. The addiction grew to such an extent that in the year 2000, he attempted selling his kidney to buy drugs. But he was detected with Hepatitis C and was sent back.

Later, during his wife's pregnancy period they both were diagnosed HIV positive. The virus was very active in their body.

“At the Voluntary Counselling and Testing (VCT) centre, a male and a female counsellor quietly sat in front of us. My knowledge of HIV was limited. Till then I knew only that HIV happens due to sex and the HIV positive person has to die an untimely death. It was only when I was diagnosed HIV positive that I came to know that the infection also spreads through contaminated syringes.”

Those were the days when the awareness and advocacy campaigns were built around the concept of creating a fear of the infection in people. “The advertisement on television showed a man vanishing slowly leaving a question mark behind. The transformation was followed by a slogan ‘stay away from HIV or you would disappear like me’.

“In front of my wife I would put up a brave face and pretend as though nothing had changed. But I would go to the wilderness and there I would scream and cry and vent my frustration. Slowly, my dependence on drugs increased.”

Wanda's father tried to help by sending him to a rehabilitation centre, but it did not help. What changed Wangda's life was his time in prison. On several occasions he was sent to prison—for two weeks, 48 days and the longest stint was for over three years.

“Prison did a lot of good to me. I started meditating and reading a lot. I made a lot of friends there and started teaching everyone the harmful effects of drugs. I was liked by all in the prison. When my term in prison ended, a large number of inmates gathered to see me off. Outside the prison, my wife and children were waiting for me. It was overwhelming!” Wangda looked at his children (four of them and all had been tested negative) and wife and realised that he was being unfair to them.

His life changed further when he attended the PLHIV meeting organised by Ministry of Health in 2009, where it was decided to form an organisation of PLHIV. Wangda volunteered to head it. “This gave me a purpose to live,” said Wangda.

“At that time I had wished to help all PLHIVs if one day I became a millionaire. Today, that wish has been granted—Lhak-Sam has grants worth millions and I am able to support the positive people like me,” Wangda said.

## **(8) Do negative people live longer?**

When 19 year old Tshering Choden carried her baby to the hospital, her landlady accompanied her. The baby was crying and Tshering, despite trying hard, was unable to pacify the baby. The landlady insisted that she should breastfeed the baby. Tshering being HIV positive could not feed the baby and therefore she made up an excuse that she had forgotten to bring the baby food. The excuse could not satisfy the landlady, who sarcastically told Tshering that she must be HIV positive and that is the reason why she was not feeding her own baby.

Young Tshering, who was infected with HIV but did not know much about it, felt humiliated and embarrassed, yet she denied and retorted, “I am not HIV positive. Had I been infected with HIV I would have died a long time back.”

Now 25, Tshering asks a pertinent question: “Do negative people live longer and better as compared to people who are positive?”

She answers her own question, “With Anti-Retroviral Therapy (ART) it is possible for an HIV positive person to prolong his/her life besides improving its quality.”

Tshering’s wisdom and understanding can amaze anyone, especially when a person comes to know that she has never been to school and she has never worked outside home either.

Tshering was tested positive when she was carrying her second child. The news scared her of the discrimination that she and her child would have to face. She was sad and embarrassed but she was too young and ignorant to ask any questions from the counsellor. The only concern, which she could voice, was the safety of her child.

“The nurse in the hospital tried to assure me that there were medicines that reduce the chances of mothers transmitting infection to their babies. But I did not believe her. The real counselling was done by my husband and the rest of the family members, who were very supportive and understanding.”

Strengthened and encouraged by her family’s support, she decided to share her status with people and came before the media in 2011. “I wanted to give a strong message to people to encourage them to go for voluntary testing.”

Now Tshering goes for advocacy with Lhak-Sam members and emphasises that all pregnant women should go for check-ups in order to avoid transmitting the infection to their babies.

## **CHAPTER TWO**

### **POSITIVE SUPPORT**

***“Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.”***

***- Leo Buscaglia***

Felice Leonardo “Leo Buscaglia”, who said these inspiring words in one of his motivational speeches, was also known as Dr Love. The Italian author was also a professor in the Department of Special Education in the University of Southern California. Leo Buscaglia was called Dr Love for the simple reason that he acknowledged the power of love, which can make people change.

It would not have been possible for the people whose stories are narrated above, to embrace their lives without the power of love.

There were people, agencies and organisations that also understood this powerful tool to help HIV positive people in finding a purpose in life. The

brave hearts did not require physical help but needed moral and emotional backing. They needed to be told that they are still loved and desired, irrespective of their positive status.

## **Practice what you preach**

### **Lhak-Sam – A Network of People Living with HIV**

The literal English translation of the Bhutanese word ‘Lhak-Sam’ is ‘altruism’, which the Oxford dictionary defines as—‘disinterested and selfless concern for the well being of others’.

The very meaning of the word is embedded deep behind the formation of Lhak-Sam, which is an endeavour of a group of people living with HIV. The network has got the support of Ministry of Health, Royal Government of Bhutan and a few dedicated individuals. Lhak-Sam was born in 2009 by the courage of HIV positive people who got financial and technical assistance from UNDP, UNAIDS and Civil Society Organisation Fund Facility (CSOFF).

Taking the HIV Programme to a next level, the Ministry of Health in 2009 sent four PLHIV to Bangkok on a study tour.

“The tour was an eye opener. We met many positive people who were doing lot of work for other positive persons. We brought back lot of reading material from there and for the next 14 months I read all the time. I learnt a lot about HIV and AIDS,” Lhak-Sam Executive Director, Wangda Dorji says.

A few months later, the Ministry of Health brought together 13 PLHIV in Paro district. This was the second occasion when the positive people in Bhutan met with each other.

Wangda explains the genesis behind Lhak-Sam “It not only boosted our morale but also gave us a lot of information relating to our rights. It was decided in the meeting to form a group to help each other as the government cannot reach everyone. The group aimed to be a forum where those suffering alone due to self stigmatisation or facing discrimination, would find it easy to share their concerns and would also get some help.”

“It is only the beginning of a long journey. Lhak-Sam has the opportunity to bring a real change,” says Claire Van Der Vaeren, the United Nations Resident Coordinator, in Bhutan.

Claire reiterates, “Lhak-Sam has been instrumental in pushing away the stigma and discrimination. Although even the Lhak-Sam members were apprehensive about their acceptance in society before declaring their status, but the response was positive. People are now compassionate towards PLHIV. I am stunned to see the impact although it is happening very quietly and on individual basis.”

Lhak-Sam became the tenth organisation to get registered under the CSO Act in Bhutan, in November 2010. On December 1, 2010, the organisation observed World AIDS Day with the support of Ministry of Health. For the first time families of PLHIV met each other. However, it remained a private affair. The public declaration came after a year.

A saying goes like this—“Cry and you cry alone; laugh and the world laughs with you”. One step from PLHIV and support poured in from different quarters. The seed money came from chief abbot (Jekhenpo), His Majesty the King, Her Royal Highness Ashi Kelzang Wangmo Wangchuk, some corporate houses and few good individuals. UNAIDS and UNDP gave US\$

9,000 and US\$ 67,000, respectively. The organisation also got a Nu.1 million grant from CSOFF.

As a young organisation Lhak-Sam is mentored by RENEW. “We will provide them with trainings on proposal writing and report writing besides regular organisational development exercises on their own, to make them self reliant by 2013.” RENEW’s Executive Director, Chimi Wangmo says.

The capacity building of Lhak-Sam members also involve a Treatment Literacy Programme organised by Asia-Pacific Network (APN+) and peer outreach work by Mercy Foundation of Bangkok.

As of date in 2012, Lhak-Sam has 107 members, which include 10 children as well. Five of its members (PLHIV) shared their status with the world in December 2011, after which they involved themselves in extensive advocacy in different parts of the country.

The advocacy is mostly with school students, police and armed personnel. First, Lhak-Sam seeks permission from the District Health Officer and then the target audience is invited. The advocacy starts with PLHIV sharing their lives’ experiences with the audience. Later, the audience too is encouraged to raise their queries and get their doubts clarified.

“Even though in nascent stage, the organisation has already started working as a bridge between people living with HIV and the service providers,” says Namgay Tshering, the National AIDS Control Programme Manager.

“Formation of Lhak-Sam is a step forward in our effort to achieve the landmark of ‘zero new HIV infection by 2015’. The group has a major role to play in peer education through their experience sharing. We are nurturing them as an NGO,” says Yeshey Dorji, the Assistant Resident Representative UNFPA.

## **VCT Centres**

### **I thought I chose the wrong profession!**

In April 1993 a couple in their twenties came to the Public Health Laboratory with complaint of STI. At that time, no consent was required and no counselling was offered to patients for conducting sensitive tests. The husband was tested positive for both STI and HIV. Later, the wife too was advised to go for the test. The husband died of cerebral malaria a year after the detection.

“Although I was not involved in this case, I thought people who received life threatening test result news should be properly counselled. I started studying literature developed by WHO and other such agencies and on my own started counselling,” says Ngawang Choida, Bhutan’s first VCT Counsellor.

It was early 1990s and Ngawang was a lab technician at the Public Health Laboratory. The norm at that time was that the technician who collected the sample was responsible for handling the case as well. Recognising his initiative and interest, the Ministry of Health formally made Ngawang the first VCT counsellor in 1996.

He reminisces about his interest in counselling, “I used to take personal interest in my patients and always treated them as my family members so that they were comfortable with me.”

There was no treatment available in the 90s.

Recalling the case of a 26 year old man, who was diagnosed HIV positive, Ngawang says, “I had to do a lot of probing and questioning to find out his risky behaviour before persuading him to go for HIV testing. He was tested positive. When he was informed about his HIV positive status, he could not believe his ears. He went blank.”

“In the 90s, people were not familiar with HIV virus, its dynamics and difference between HIV infection and AIDS. What they knew was that AIDS was a deadly disease. Television and radio used to advertise the whole day...

‘AIDS is a killer or AIDS is a passport to death’. There was no information dissemination on difference in HIV and AIDS.”

“I gave him time to soak in the news and then encouraged him to talk. He started crying. He thought he was going to die. I was in a dilemma. I thought I had chosen the wrong profession. I was giving people the shocking information but I had no remedy and can offer no support to them. I had become a demon, giving death sentence to people.”

Till 2004 there were no guidelines for treatment of HIV, in Bhutan. The turning point came that year when a Royal Decree was issued that mandated treatment and medication for all those living with HIV. The Royal Decree ensured equal rights to HIV positive persons and made tackling of the infection a collective responsibility of all Bhutanese citizens.

The situation has improved manifold since 2004. Awareness has increased, due to which people with risk behaviour volunteer for testing. Testing facilities are available even at the district level.

Today in 2012 Bhutan also has four Health Information Service Centres, which provide information, counselling, testing and treatment facilities for HIV and STI. While earlier, due to lack of awareness these centres had poor turnouts, the year 2010 saw 2,362 clients registering at the centre.

## **CHAPTER THREE**

### **POSITIVE RESPONSE**

***“Consciously or unconsciously, every one of us does render some service or other. If we cultivate the habit of doing this service deliberately, our desire for service will steadily grow stronger, and will make not only our own happiness, but that of the world at large.”***

- ***MK Gandhi***

When Mahatma Gandhi said these lines he had not thought that so many would be inspired by his words.

Now, there are philanthropists and agencies rendering selfless services to the needy. These services are steadily growing and becoming better improving many lives around the world.

The brave hearts living with their positive status and those supporting them—both get the backing of these national and international agencies. The efforts of the affected would see its outcomes in a more efficient and effective manner with the technical and financial backing of these philanthropists and organisations.

## **Joint UN response to HIV in Bhutan**

The UNAIDS and its co-sponsors of UNAIDS support the national response to HIV/AIDS in Bhutan in different ways.

UNAIDS provided financial and technical support to nurture and capacitate network of people living with HIV in Bhutan.

Besides, UNAIDS facilitated several research and training programmes in the country. This includes ‘Development of Epidemiologic Profile 2010’, training on data management’, ‘training on ART, ‘training of Lhak-Sam on advocacy’, PAF support to Lhak-Sam, support to the review of NACP, development and costing of the National Strategic Plan and Operational Plan, development of Global Fund proposal- round 9 and many more such activities.

UNICEF extends technical support to NACP, Ministry of Health, in the area of PMTCT and VCT. The agency trained 66 health care providers on PMTCT and VCT functioning in 2009. A gynaecologist was sent to Bangkok for PMTCT training course, whereas two laboratory staff were trained on the use of Polymerase Chain Reaction (PCR) machines for Early Infant Diagnosis (EID) of HIV infection in 2010.

WHO provides support to NACP for dissemination of information on global initiatives, in strategic planning for health sector response and for building capacities to enable their adaptation into strategic and operational plans. WHO also supports capacity building for adaptation of WHO recommended tools for agreed interventions. In 2010, two staff members from Ministry of Health were sent to Indonesia for training in strategic planning for health sector response to HIV/AIDS and two medical officers were trained in Sri Lanka on training of trainers on HIV counselling. WHO also supported training of health staff in CD4 tests.

“Efforts to increase the general awareness about HIV infection have been made in Bhutan over the years, notably through multidisciplinary teams at the Dzongkhag (district) level. Although most of the time the efforts happen in bursts, it has been possible to sustain the general population’s attention on a continued basis. The issue is integrated in school education, and media also gets involved in voluntary campaigning from time to time” says Claire Van Der Vaeren, UN Resident Coordinator in Bhutan.

With the support of UNFPA's Goodwill Ambassador, Her Majesty, the Queen Mother, Ashi Sangay Choden Wangchuck, an annual campaign is also undertaken nationwide on World AIDS Day. The issue has been integrated into government’s approach to public health as well.

“With rising awareness levels, people have started feeling compassion for those living with HIV. Yet stigma persists and a lot needs to be done. Lhak-Sam has made a beginning in this regard,” says Claire.

When Lhak-Sam members revealed their status in 2011 they were also apprehensive whether people would accept them or not, but the response they received was positive. Now other positive people are reaching out to them. The change is happening very quietly and evidence to it is the increasing number of reported cases. Three years ago, Bhutan had 168 reported cases of HIV and the number went up to 270 in 2010.

“In Bhutan, 90 per cent of the HIV infection is mainly due to unsafe heterosexual behaviour whereas 0.8 per cent is mother to child transmission. The critical high risk population that are yet to be reached is migrant workers, men who have sex with men and sex workers. There is no or limited advocacy targeted towards them, since it is difficult to pin-point these sections of population. Injecting Drug Users are present in Bhutan but not rampant,” Claire explains.

To cover all the vulnerable population groups, knowledge and awareness needs to be constantly reaffirmed as there are lot of misconceptions besides maintaining the advocacy chain.

With this premise, UNFPA and GFTFM are supporting Government of Bhutan in the development and implementation of Life Skills Education (LSE) programme in schools through training of in-service teachers.

“So far, a critical mass of teachers has been trained, covering schools in 15 districts. By 2013 all teachers would be trained on LSE in Bhutan and would have the knowledge of HIV—the infection and its prevention,” says Yeshey Dorji, the Assistant Resident Representative, UNFPA.

Further, since 2011, UNFPA started working with Bhutan's Nun Foundation and is now involved in creating awareness and training instructors on LSE. The training is the first to educate the nuns on how to save and protect themselves and then to raise awareness among others.

UNFPA is also involved in condom promotion through social marketing. Boxes of condoms can be found kept at prominent places in front of all Drayangs (Dance Bars), hotels, discotheques or other public places visited by youngsters.

## **National HIV/AIDS Control Programme**

The National HIV/AIDS Control Program was initiated in 1988 by the Government of Bhutan, six years before the first ever HIV case was reported in the country. Since its inception, the programme's focus has been on public education and capacity development of health workers.

In a feature unique to Bhutan, apart from the coordinated government efforts, a testimony of the commitment to respond to HIV is the explicit top-level initiative from the Royal Family. On May 24, 2004, the Fourth King, His Majesty Jigme Singye Wangchuk, issued a Royal Decree to participate in the HIV prevention and to respect the rights of PLHIV. During the same year, the Royal Edict broadened the scope of the organisational and individual-level participation in HIV prevention.

Bhutan received its first financial aid from the World Bank for period of five years, starting from 2004. The four major components of the intervention were:

- HIV and STI prevention and promotive services
- Scaling up of treatment and care services
- Building institutional capacities and training health service providers
- Strategic information—promoting research-based studies and surveys

In 2005, with the growing rate of infection among the younger generation, the Fifth King, His Majesty Jigme Khesar Namgyel Wangchuck, proclaimed

to the nation, “HIV/AIDS is no exception. The youth will use their strength of character to reject undesirable activities; their compassion to aid those afflicted and their will to prevent its spread.”

Meanwhile, in 2008 Bhutan got more financial support from the Global Fund for HIV/AIDS, TB and Malaria. The major emphasis of the Global Fund support was to reach the most vulnerable sections of population including youth through coordinated multi-sectoral response.

Her Majesty, the Queen Ashi Sangay Choden Wangchuck also works with the grass-root communities for HIV prevention, substance abuse and reproductive health issues, especially pertaining to teenage pregnancy.

“Our achievements have been possible primarily because of the high level commitment, leadership and coordinated multi-sectoral response in combating the HIV epidemic in the country. Diagnostic facilities have been strengthened to enhance the case detection rate at all levels and treatment services scaled-up to treat all infected individuals who are in need of lifelong ART treatment. The success in our national response is partly attributable to the endeavours of the district based Multi Sectoral Task Forces in carrying out general awareness programmes in all the 20 districts and within its administrative blocks. Bhutan now needs to focus on detection through sustained logistical support to reach the optimum level of infections” says Namgey Tshering, the Programme Manager National HIV/AIDS Control Programme.

As stated earlier, Bhutan is one of the few countries in South Asia that continue to experience a low HIV prevalence of below 0.1 per cent. The programme’s cohort data on HIV status indicates that almost 90 per cent of the infection is attributable to unsafe sex and remaining 9 per cent to mother-to-child transmission. Hence, acknowledging the UNAIDS vision of ‘Getting to Zero’ and “Millennium Development Goal”, Bhutan is embarking on achieving zero new HIV infections by 2015. To achieve this goal, Bhutan

will scale up the HIV screening facilities to allow all ANC attendees to undergo voluntary testing for HIV.

Mr Tshering adds, “This would require reaching out to every ANC attendee and giving them a complete package of preventive, promotive care and treatment services. Our focus will be on community focused public health intervention, so that right things are delivered to the right people in the right time and the right way.”

However, the biggest challenges that still remain are the future financial sustainability of the programme’s interventions and shortage of manpower at the national programme level.

The World Bank project, which provided US\$ 5.7 million for strengthening HIV related health care systems and capacities, ended in June 2011. The Global Fund Round Six brought US\$ 2.9 million, which too is ending. The country needs more funds if it hopes to accomplish the goals it has set for itself.

Mr Tshering is hopeful of procuring financial support. “We are now exploring the support from all the multilateral and bilateral donor agencies. The National Strategic Plan-II has been developed with major emphasis on the target-based approach to ensure financial sustainability of programme interventions. The National Strategic Plan-II is also aligned with 11<sup>th</sup> Five Year Plan to achieve maximum outcomes within our capacity. Recently, we have also submitted a proposal under Global Fund Transitional Funding Mechanism, amounting to US\$ 1.14 million for a period of 2 years. The primary objective of this proposal is to sustain the past gains and ensure that there is no major disruption in the delivery of essential services. We are hopeful that our collaboration with our UN development partners will be further strengthened and support from donor agencies will be mobilised with evidence based country proposals.”

## **THE LAST WORD**

Bhutan keeps the National Gross Happiness (NGH) as a parameter to gauge its success and growth as a nation. The concerted effort to attain success over HIV infection is just one of the many steps in that direction. The country has dared to face the challenge and is confident of a great victory. The following lines beautifully describe Bhutan's endeavours...

***“Failures are made by those who fail to dare and not by those who dare to fail.”***

***- Lester B Pearson  
Nobel peace prize winner in 1975***