



DOWN,
BUT NOT
OUT

Babli's Story



A Family Tale
Coming to Terms with Depression

By Dr. Surekha Ramachandran

Chapter 1.....

A BROTHER'S PERSPECTIVE

(Rahul Ramachandran)

I was not made to feel special when I was younger. On the contrary, my little sister was actually given a lot more attention and she seemed to be the apple of everybody's eyes. Yes, jealousy does set in when you are a 5-6 year old who had enjoyed undivided attention until then and suddenly someone else gets pride of place.

But then Babli was special. Apologies, is special. And this I realized when my mom sat down with me one day and explained to me why Babli was being given the attention she was. Mom told me that I should be proud of my sister who is a fighter from birth. Her multiple surgeries which would probably have broken many grown adults, only made my baby sister stronger and even today, I can proudly say that Babli is a far stronger individual than I am.

I started feeling very protective about Babli. I would not allow anybody to hurt her. She was the soul of the family. With her bubbly nature and her infectious laughter she could lighten any mood and make all of us feel so much better. She was and still is my stress buster. But I did realize that she seldom needed anyone to protect her. She was as good as any other child that I knew. Like every brother sister relationships, we had our shares of love and quarrels. And she would never back down. It was always me, because Babli knew how to get her way.

And then came this big shock - Depression. Like I had heard everybody say - Depression was alien to people with Down syndrome. I have seen Babli undergo this torment and let me tell you it is really gut-wrenching to see someone you love undergo so much trauma. It suddenly seemed to me as though she hated me. I wanted to be loved by her. I wanted to protect her. I wanted her to know that come what may I was always there for her. But she wanted nothing of that. She wanted to be left alone.

And seeing her like this was traumatic for my parents too. It was as if our entire family had lost their laughter, their joy. My mom and dad were almost as listless as Babli herself looked. And there was nothing I could do to bring back the Babli who infused life into our family.

I felt so unwanted by Babli. She would not talk to me properly. Whenever I tried to speak to her, she used to either ignore me or send me off. I felt that she was seeing through me during those days. It was not only me, it was with almost everyone – mother, my father, our helpers, her carer, she spared no one. It was so unlike her usual self. It was as if we were seeing another person who had inhabited Babli's body. This entire phase was something I wish I could forget. I wanted Babli to come back. It seemed like she was going away from all of us – closer to someone who was a figment of her imagination. She was talking to herself, crying by herself and behaving very differently.

But thanks to the doctors and my mother's feisty nature, Babli is back with a bang. She is her usual bubbly self – the center of attention, adored by my children and loved by my wife. Babli is back to giving me the mental strength that she did before her brush with depression. She does her swimming, yoga, dance and meditation. She radiates inner peace and warmth and to me she is extra special – probably because that extra chromosome of hers that makes her stand out in a crowd!

Depression can be a silent killer, but as a brother, I knew that standing by her was the only way to tide Babli out of it. During that period Babli did not know what she was doing and why? But I certainly did. So if I had not been there to hold her hand when she needed me the most, I would have failed in my duty as a brother. This holds good for every sibling there whose sister or brother with Down syndrome is undergoing this torture. I realized that they needed our support at every stage and more so during those depressive times.



Chapter 2.....

THE FIRST HURDLE

Babli was born on the 8 January 1981. For the next few days after the birth I stayed in hospital, during which time a great number of doctors visited me on the pretext of checking the infant. I had no clue that there might any medical issues. After three weeks I was very gently told that Babli was born with bilateral cataracts that needed immediate attention, by way of surgery. A week later she was back in the operating theatre for follow up surgery.

This was the start a long and arduous journey of meetings with an ophthalmologist, a surgeon and an anesthetist. Dates had been fixed for the appropriate surgery and I assumed that was the extent of the news I would receive about my daughter's health.

Eight months later and all the surgeries had been completed. Babli had been fitted with contact lenses and there was a small sense of relief that her life had been sorted out. Then another curveball was thrown into the mix. I was informed that Babli had to be tested for what was in those days was termed as Mongol or Blue Baby. The blood would be collected from her foot and as we had no labs in Chennai, the blood sample had to be taken to Vellore.

The doctors said it was a simple blood test to confirm whether or not the child had Down syndrome. I had no idea what this test was about or what exactly Down syndrome was. We lead very sheltered lives in India at the time and I had never been exposed to people with disabilities. If a child did have disabilities of any variety, we were not allowed to interact with them and our parents would avoid those families. Crazy, but true.

It's difficult to recall what my initial reaction was as I was in a daze. Nothing seemed to connect and I could only hear my son screaming for a sharpener to sharpen his pencils. When I seemed to have come down to earth, my only question at that time to the consulting Doctor was, "Will she ever feel pain?", because the general consensus from the experts was that people with Down syndrome could not. That too was dismissed and I could sense an uneasiness to my queries.

Everything seemed to have come to a standstill. Despite being a mental wreck, I trying to control my emotions as I did not wish to exhibit any form of stress in front of my son, Rahul. Nothing seemed the same now. In fact, my main concern now was Rahul. How was I supposed to divide my time between him and Babli and still come to terms with the implications of her disability on the family? I was being sucked into an abyss and I could not see any way to save myself or the situation.

For all of us whose children were born in the early 80's, there was near on no information, no communication, no print media, no books and certainly no Google. This dearth of information left us helpless.

Whichever direction I looked at, I was told that my child would never be 'normal.' I remember vividly a pediatrician who claimed very loudly that my child was a 'waste'. Being feisty and determined I challenged him that in a few years I would bring the same child and prove him wrong...and that I certainly did! I had no intention of letting any 'experts' tell me that she had no future. We all have a future and Babli was no exception

At 20 months she also developed a severe respiratory infection, which ended in pneumonia and instead of treating her, all medical professionals, predicted that she would not be in a position to fight this infection. One Doctor actually took an X-ray and said she would not last through that night. I remember slapping him and said I would fight this infection with her and together she would overcome it. For six weeks I stayed close to my child talking and singing to her. I do not know if miracles exist, but it worked and my child came back to us.

Babli's bilateral cataracts eventually developed into glaucoma, which resulted in further surgery aged two years old. Another set back for her vision. Those few months she could not wear her contact lenses.

Every time we had her eyes checked she would be wheeled into a dark room, which then contributed to her having a fear of being in dark rooms.

One major problem that Babli faced was severe constipation. We had no methods to check thyroid levels and I was not aware that she had hypothyroid. She was also born with severe hypotonia, (when a baby's muscles are relaxed. Many referred to the baby as 'floppy' at this time). Babli would be administered an enema every single day and at three years she would hide under the bed because she did not want enema. Passing stools that are not firm, but when they are like stones, is the most painful process and to watch your child in pain and be helpless can also be emotionally draining on the parent as is physically on the child.

I often questioned the existence of God during those years. If there was a God then how could he see one infant suffering from multiple challenges. When would she call me Ma? Would she ever speak? Would she come asking for her favourite toys? Questions that would race through my head.

But we were all in for a shock. A bigger shock than the doctors predicted or many expected. She started to answer all my questions and more.

Yes, she has her limitations, but she keeps within her boundaries. She is capable of looking after herself in unfamiliar surroundings and can report every incident that has either excited or upset her. When Babli needs help, she's not shy in asking!

I'd go as far as saying it is Babli that has kept our family together. She has kept us grounded and taught me the art of sharing. Giving comes naturally to her and she has taught me to care and give.



Chapter 3.....

THE START OF A NEW JOURNEY

*I*t took a while to come to terms with the implications of my child having Down syndrome and how the landscape might change as a result. However, one thing that helped was that her behaviour and condition was constant. We knew what to expect with Babli.

Then something started to happen in her late teens which was different. A change in her character, her mood, her persona. She started talking to herself a great deal and hallucinations started to become common place. She no longer related to people, especially myself, which was the biggest shock. Initially, we all thought she may have been deliberately sulking, which from everyone else's perspective proved to be nothing short of irritating. You could see that Babli couldn't overcome her state of mind by just thinking positively, or from the people around her telling her to 'Snap out of it.' It's almost as her mood stabiliser had been removed. She'd lost the capacity to fight being upset. As Babli was battling her inner torment, we also started to share that sense of helplessness.

I soon realized that whatever Babli was battling came with a far more complex set of baggage than sulking or sadness. Babli's chatty persona had almost been extinguished and this meant she couldn't express herself as well as she might have wanted to and it seemed that her previous skills and strengths across the board had also been substantially dampened. That's not to say that a change in her persona meant she was depressed, it was just a signal - one of many.

Here's a list of some of the signals and symptom changes that I recognized in Babli:

- Low self-worth.
- Negative self-talk.
- Agitation.
- Aggression.
- Trouble falling or staying asleep (waking up one or more times during the night shortly after going to bed. In addition, Babli could sleep only 45 minutes at a time).

- Mood swings.
- Anxiety.
- Difficulty concentrating.
- Facial tics.
- Eating disorders.
- Chronic pain.
- Difficulty swallowing.
- Hiccupping or burping (from swallowing air).
- Obsessive thoughts.
- Repetitive behavior.
- Isolation and lack of interest in social events.
- Inability to deal with changes in routine or stress.

These were worrying and helplessly desperate times. It was obvious that she was harbouring a mental health condition of some sort, so we took her to the doctors. The initial response from the experts was shocking and ignorant. They claimed that 'this' was absolutely normal for people with Down syndrome. It turned out, 'this,' was depression - an illness which is both suffocating and draining, and for many a very lonely place to be.

You will often hear people say, 'It's good to talk,' referring to depression, but most of the time, many won't know they are suffering. The more depressed they become the less they will want to socialize with groups of people. As the old expression goes, 'Being in a crowded room can be the loneliest place.' Many will think they are either crazy or going crazy and will keep asking themselves, 'Why? Why? Why?'. For those around them, they won't know what the symptoms are and will most likely just think the person is down in the dumps and has the capacity to pull themselves out of the rut.

From my side, I'll be honest when I say I was struggling. Everything that was positive in my life was not strong enough to give me the strength I needed to pull myself forward. A good education, nice job, comfortable lifestyle, close friends, a great family and a happy marriage. None of it mattered. In those first few years, I lost my sense of purpose, self esteem, my health and almost my life.

Thankfully, in India, right from childhood we have been taught the importance of family in our lives. It is a well-oiled system. And when a member has a condition like depression, it can cause disruption that can significantly impact other family members. Depression is a condition that can either divide a family or help bring it closer together. Thankfully it brought ours closer.

However, I soon realized that there was a dichotomy amongst friends and family in terms of who was willing to help. Some simply didn't know what to do or say, saw it as a sign of weakness, or felt ill equipped to deal with the situation. Consequently, they ended up distancing themselves. The balance of the people were forthcoming in support, even if they didn't know how and when they'd be able to offer it. This also posed a problem – over active family and friends who were trying too hard to take responsibility to fight alongside Babli and make her recover quickly, which on occasions became counter-productive.

However, those who did become involved also became affected. Some more than others, depending on the extent of time they spent with Babli. It's almost as if they got caught into a slipstream of secondary depression, especially in those early stages of uncertainty.

When things seem to makes no sense, your head gets scrambled. You start to question rational thoughts and beliefs and it was during this phase that I started to question the existence of God. Did he really come to our rescue or was he there to watch and torture. Is this "The God"? I thought I had done with the questioning at Babli's birth, when I never found an answer to my innumerable questions of why, what, when and how this child had entered my life? After 16 years of learning to live with a person born with Down syndrome, who had to face every medical challenge that could be associated with the syndrome, having come to terms with it and having exhausted all my energies into raising a perfectly beautiful girl, here came the worst disease...depression.

If there's one bit of advice I'd like to give to those helping a loved one in those early stages of depression – educate yourselves and seek professionals in the medical industry who are genuinely qualified to converse about depression. This in turn will allow you to assist the individual in getting the appropriate treatment and support they require.

However, back then I had a fear of meeting with the professionals. I did not want to hear them talk of institutional care, which was a constant refrain when Babli was born. Nonetheless, what was more worrying, was their mindset. I had been told that she had Down syndrome so she could not be depressed. What utter rubbish. Every time I took Babli to the so called specialists with a medical issue, it was usually the same answer. "It's impossible for her to feel pain like anyone else. She has Down syndrome." Or, 'This is normal for a person with Down syndrome.' It was as if the condition was a carpet for which all medical issues, physical, mental or otherwise, could be swept under. This was no different. "'They' cannot have depression, because they do not have a brain.

Therefore, they cannot think or reason, so how can they be depressed. Go home and leave her as she is.” One of the doctors even tried to flip it on me and said I was the one depressed and even prescribed me medication.

It enraged me and made me very sad all in one swoop. Even worse, Babli was present with me when they were explaining their ‘professional,’ opinions and had to hear her self esteem lowered by a group of ignorant, indifferent and careless individuals, who were too lazy to offer assistance or attempt to move their boundaries of knowledge to a higher level to come back with relevant and practical solutions.

However, if there’s one thing I know about myself and is that I don’t quit. Yes, I was angry and very sad, but those emotions were also very powerful motives to ensure I proved them wrong and Babli right.

It was obvious I still needed to consult with professionals with genuine knowledge and understanding as opposed to the buffoons I’d spoken with previously. Whilst searching for the appropriate people, I looked at my friends and confided in my son, Rahul.

While getting to grips with Babli’s mental health, I decided to research depression and brush up on its previous victims. It turns out it depression doesn’t discriminate. (I can almost see those ‘professionals’ scratching their heads in amazement as I continue with my dialogue). Rich, poor, with disabilities, without, anybody on this planet could potentially be struck with depression.

I had read that Abraham Lincoln suffered from depression. Sigmund Freud, Mark Twain and Winston Churchill too. Lincoln’s longtime law partner William Herndon observed about Lincoln, “Gloom and sadness were his predominant state,” and “His melancholy dripped from him as he walked.” And another Lincoln friend reported, “Lincoln told me he felt like committing suicide often.” This unfortunately was another common platform which Babli would share during this period. She tried to jump into a well and also took a knife to cut herself. She would say, “See the pain in my face, my eyes. Take it away. She cried for days telling us she wanted out.” These are probably some of the worst memories of my life, but thankfully we got through the hard times and all learned many lessons.

Looking back, the mental torture was near on unbearable for me also. Once, during one of those days of pain, I was asked what could be done for me. My reply, “Make me unconscious.” Exactly the way a person in depression would react if they could express themselves. Anything to get rid of this maddening pain.

Abraham Lincoln, along with other famous sufferers of depression, used humor as an antidote to depression. To boost his spirits, Lincoln told jokes and funny stories. Lincoln said, “If it were not for these stories—jokes—jests I should die; they give vent—are the vents of my moods and gloom.” Joshua Wolf Shenk concludes that “Humor gave Lincoln protection from his mental storms. It distracted him and gave him relief and pleasure . . . Humor also gave Lincoln a way to connect with people.”

All this gave me hope. Babli was my Lincoln, my Mark Twain. She epitomized a strength, courage and determination in the way she was battling depression head on. There was no way I was going to let her slide any further unnecessarily or myself for that matter. It was time to fight back at this vile ‘D’ word with knowledge and will-power, but I also needed all my support systems, namely my best friends and my family, who had been with me while I was raising Babli. I soon learnt that keeping Babli with friends and good company was very crucial. As the old expression goes, ‘We are all products of our own environment.’ I needed to try and assist in making a wholesome one for my daughter, which could assist with improving her up and coming battle with depression.

Once realization did dawn, as a mother, I knew that I could help other parents undergoing the same hardships. So, I made day to day reports on Babli’s behavioural changes and also took pictures without realizing that she was going through severe mood changes.

What you are about to read is Babli’s diarized version of depression, as noticed by myself and her carers. This is the compilation of those bleak days where I felt I was losing my daughter to this vile disease, and finally the rays of hope that led to our redemption and my Babli came back to me as before. It’s not a one size fits all account, more a document which I hope you can pull some threads from and hopefully add to in your own situation.

Any periods, such as, from 2001-2002, and all of 2004, Babli was stable. Hence no diary dialogue.



**I feel tired, listless, help-
less and feel like shutting
myself from this big
world...there is no color, no
happiness, no air.....mom i
feel suffocated. help!!!!!!**

Chapter 4.....

DEPRESSION

(Babli's latest Test)

1 May 1999 - 15 June 1999

Even prior to the recording of this diary, a number of people who were close to Babli, such as her friends, carers at home and in school, noticed that she would drift away and get angry and sulk without reason. She started relating with an unknown, unseen being (she claimed it to be God). She would talk to Amman (a Hindu goddess) or her favorite heroes.

Since she was behaving differently and I was travelling, I decided to take her with me to London. I thought the change of scenery might help. Unfortunately, she was against the idea from the beginning. We tried to amuse her by taking her to the theme parks which used to excite her previously and despite a wee positive change in her mood, she was constantly drifting away. One minute she was aware of her surroundings and the next she was indifferent and would have a blank look on her face. All through the trip she would have on her head phones and listen to her music loudly, which had a maddening beat. The music consequently seemed to put her in a trance and she hated me interrupting it.

What I had also noticed was that she had unpredictable mood swings from happy to sad, perhaps indicating that she may also be on the bipolar spectrum. Bipolar disorder, known previously as manic depression, is a condition that can see an individual swinging between two polar opposite moods – depression and mania. Whilst depressive they will feel and act very lethargic and whilst manic, they will be overactive, very chatty and sleep very little.

Sometimes Babli could be very happy and joined everyone in conversations. She would crack jokes and laugh through the whole thing. A little while after which she would turn her face away, would not answer any one and seemed to be relating to some other person. She did not seem to like us intruding and would get very angry if I asked her to do something when she was in such a state and screamed at me

or the carer.

She said, “I feel tired, helpless and feel like shutting myself from this big world. There is no color, no happiness, no air. Mom I feel suffocated. Help.”

Her sleeping patterns were also irregular. Sometimes she would sleep at 2am and wake up in the middle of the afternoon. It started disturbing me, as she would say that she was scared of the room. So we shifted her upstairs. Firstly to my room and then to Rahul’s room. Even there she was not sleeping too well. So we had to give her a dose of Phenergan. Unfortunately, not even that settled her down.

We decided to stop her sleeping during the day and for some nights she would sleep well and other times not at all. We decided not to leave her alone for long periods of time and friends started coming over taking turns to spend time talking to Babli. We were fortunate that we had a number of friends who were spending quality time with Babli and keeping her occupied throughout the day. However, one day she took it out on my mother-in-law’s nurse, as Babli felt that the nurse was causing trouble. So we promised her the nurse would leave. But from then on we were all very careful with our choice of words and made sure that we did not use any negative statements. Babli’s anger was always directed at me, which was heartbreaking as we had always been best of friends. She had strong feelings of hate or love for me and she would exhibit both of them without any second thoughts. I felt as lost as she did.

A few words from Nagamma (Babli’s Carer at the time).

Babli did not sleep during the night, and used to talk about Amman all the night imaginarily.

She used to keep doing the same work again and again. She used to get angry if I tried to stop her.

She liked watching movies and during night she used to keep talking about the movies. She used to keep shaking her hands and if ask to stop this she used to get very angry.. If anyone happens to try and stop her act, she argues and starts a fight. She likes Uma Amma, Rama Amma and Lakshmi Amma. She loves God (esp Amman) and likes frequently going to temples and also likes stories related to God. She loves Rahul very much. She loves music and likes to hear it loud. She likes to go on a long drive. She likes eating beans, curd rice and gulab jamun. Whenever she goes out, she buys devotional music CD and movies CD.

And she likes to give gifts to those who are with her. She keeps talking repetitively.

She loves kids. But at times she gets angry seeing the kids. Whenever she is angry she never speaks to anyone. Even if we try to speak she will not respond. After sometime she becomes normal.

20 June 1999

For a week Babli was in a better mood, but it was not a happy mood either and this was evident. Everything around her was dull and she was unresponsive to anything we were saying. She seemed angry and upset most of the time.

21 June 1999

This was a really bad day. We were in school and she tried to involve herself in a discussion on travel, when suddenly she lapsed into silence. In the afternoon she was a little better, but by 8pm she had a dazed expression and refused to relate with us until her brother arrived. She refused to say anything after that.

Physically, her movements were very, very slow and even the manner in which she walked changed. I felt her joints were very stiff. She also seemed tired and disinterested and only brightened up when we said we were going to the temple. Nothing else seemed to motivate her. We tried to take her to the doctor but she refused to come and even struck out at me.

24 June 1999

Babli seemed to be withdrawing further and further from us. Sometimes we had to ask her the same questions a number of times and she would still not respond. She kept smiling to herself as if she was enjoying some private joke; or relating with someone else. She would get hurt very easily and seemed aware of what people were saying. She repeated words that had been said against her or words she assumed that people have said. Her imagination was running amok. It took me some time to realise that she was happy in her own 'world' and hated us in-truding into 'that' world. It upset me to see Babli in this state, especially when she said, "I don't feel hungry, I cannot stand the sight of food. Please help."

**I don't feel hungry, I cannot stand the sight of food.....
please HELP!!!!**



About this time, my niece got engaged to be married. At first Babli agreed to attend the ceremony and be a part of it. But on the 23 June, she not only refused to attend, but she refused to talk to anyone from my sister's house. It was this sister whose daughter was getting married. My sister and her daughter were kept out of the room and she refused to talk to anyone. Babli generally loves to dress and talk to people, however during this phase, she preferred to be by herself and not meet anyone. She seemed angry with the whole world. For her, it was either Babli's way or no way.

25 June 1999

Babli was good. She worked well in school. Uma, her friend, came home and spent time with her. Rama (my best friend who helped look after Babli) and Usha (also another good friend who used to visit often) also came to give Babli company. Therefore, her day seemed full. All these friends were her companions through those difficult times and they never left her alone. If it wasn't for these good friends, I might never have been fortunate enough to see Babli as happy as she is today.

On that day she seemed more responsive and spoke freely and with more sense. Now and then she would relate to an actor in her imagination, but by and large she was there with us. We went out to a restaurant and she spoke and enjoyed all our jokes. She also made up with my sister Lakshmi who she had not spoken to for 3 days. I felt that she might have been jealous of my niece and all the attention she was receiving, but she refused to comment on it.

10 July 1999

For ten days Babli had been examined by a psychiatrist Doctor Rangarajan and the orthopedic surgeon, Doctor Subramaniam. They suggested that we take a brain scan and a thyroid test for Babli. Babli cooperated very well for the blood test. But when it came to the MRI, she absolutely refused to undergo the test. She even stopped talking to anyone. During these ten days, she would shout at me when she felt like it or joke if she felt better. She was always very observant. Once when the watchman came to give me a letter she mentioned to me that his hands were shivering. I had noticed that too. Her observation skills never ceased to amaze me.

I'd like to say a quick note about Doctor Rangarajan. He was and still is an intelligent man who had sympathy with our ordeal of encountering ignorant people, but also complimented us on what we had achieved ourselves, by way of ongoing care and helping Babli to interact socially.

25 July 1999

Babli seemed better today. I could observe some good changes in her. She was responding well to music - dancing and tapping her feet or play acting. She did not seem to need any company and was very happy playing the key board. Most of those days, we took her out to a restaurant for her evening meals.

She seemed happier both at home and in school but was still very sensitive. She did not like the teacher saying that Babli had forgotten something or that she was wrong, so we had to keep encouraging her by saying that she was the best and gave her a star for her work. She did not seem so lethargic and would not keep to herself so much. She was responding very well to physiotherapy and had also starting to enjoy group therapy.

At times Babli would say things that left us in a quandary. For example - on 26 July, she said there was someone in her room waiting for her. This was around 7pm when we were going for a drive. Just like we would say we have to get home as our husbands were waiting, she felt there was someone waiting for her and imagined someone living with her.

She hated to apologize and made people bow down to her demands. During this period, she seemed even tempered and did not exhibit her usual temper tantrums. But I was not convinced since I had seen these phases of even temper which did not seem to last too long. To evaluate this kind of irregular behaviour in Babli, I had invited Kelly, a nurse from Los Angeles and Sue, a psychiatrist from California, who I had originally met at the Jack Warner Centre in Los Angeles on a visit for nutritional supplements for Babli. They had worked with people with Down syndrome in California and had agreed to come to our home and check on Babli, to see whether she had suddenly developed autism or was experiencing depression or bipolar episodes.

On the 16 August 1999, Kelly and Sue gave babli a shot of Secretin (A hormone produced by the digestive tract, which is a common treatment to aid stimulation. The drug is especially known for being administered to people with autism). Kelly said she saw immediate changes like Babli's lips turning pink, which she felt was a posi-

-tive sign. The next morning Babli woke up at 9.30 and she seemed subdued. However, in school, her work seemed quick and her responses better. She was speaking more. Sometimes we did notice that she was talking to herself and was smiling all the time. Kelly suggested that we bring her back to reality and make her more grounded instead of her taking her flights of fantasy.

She kept holding a pen in her hand and shaking it. As suggested by the therapists, we rubbed her hands and back with a hair brush to stimulate her, which seemed to aid the issue. She now began to talk more to us and was less dreamy. This gave us hope that though early, it may be the beginning of her life of reality rather than her dream world that we had been seeing for some time.

27 August 1999

The change in Babli became more evident. She continued to speak to herself but the instances were definitely less than before. She began to have better eye contact and spoke to everyone. Her love for getting involved in all activities was obvious. She even started making new statements. On Avaniavittam, a religious function, she took Aarti for her brother and father and then asked me to pour it out at the entrance of the house. I took it from her intending to complete her request, but the priest asked Babli to do it. At this, she looked at the priest and said "My mother knows nothing about these functions". We were all startled! We had never thought she would be so clear in her judgement of people. This also made us glad that she had started getting involved in activities around her, which to us was a good sign.

Rahul saw the changes in Babli more than all of us did, but we were all thrilled to see positive changes of any sort. Babli's habit of shaking her hand very often had come down and she became more attentive to words and activities around here.

Her thought process and her observation were evident in more instances than one. For example, on 29 August she told Rama that Nandan (Rama's son) had gone for a short time to study and that she should not get upset. What amazed and amused us was her comparison - "Like when mummy goes abroad I feel bad too, but I know that she will come back". Rama was moved by this simple yet profound statement from Babli.

Babli was now showing adult disposition and behaviour. She hated dressing up and detested being on stage. As a mother, I wanted her to go on stage and express herself. Once in Mangalore, I tried to send her on stage and her reaction had me stumped. She turned me down and screamed at me. She did not like becoming an exhibition on stage. She loved to dance and would dance for me, but to be paraded around like some doll was something she refused to do. That instance made me a proud mother - proud that she had her own mind and would not do something that she did not want to. She was extremely well behaved during the trip to Mangalore. Another instance of her independent nature occurred with her father. She was dressed well and stood in front of him. He was busy on the phone and paid no attention to her. I intervened and asked him to comment on her dress. His non-committal "looks nice" brought out the independent Babli who turned round and retorted "He has not even noticed me" and stomped out of the room. It was his turn to now beg for her attention. He had to plead with her, apologize and asked her to come back. My heart warmed as I saw my little baby behaving like an adult now.

27 October 1999

Babli asked for her water bed which I had thrown away. She was not happy at this and told me "I don't know why you took it away. Give it back". She actually demanded that I gave it to her right away, but that never happened, which added more fuel to her fire.

2 November 1999

Rahul told her that her head was full of dandruff and he refused to sit next to her. It maddened her so much that she walked out of the dining room angrily. It took a lot of cajoling and apologizing on Rahul's part to get her back to the table and get her to speak to him.

15 November 1999

Babli's periods were regular. I was in the kitchen and called out to her asking her to come to the kitchen and give me a kiss. She sent word through her maid Nagamath that she could not come as she had her monthly cycle.



See the pain in my face, my eyes,...take it away... she cried for days telling us she wanted out!!

4 December 1999

As the year came to an end, frustration set in, as Babli seemed to be making little contact with us. There were times when she was receptive but at that point in time, I felt that we lost the lovely talkative Babli as she continued to live in her own world. There were times when our questions and her answers were not connected. Rahul was very upset because of this and he even went to an astrologer to find out how her future would be.

As a mother, I had seen a few changes in her behaviour and habits.

- She had lost interest in food.
- She had become a slow eater.
- Her tongue seemed to hang out more than what it had been earlier. When we would ask her to close her mouth, she would get annoyed.
- To her it seemed as though we were invading her privacy all the time.
- There were a very few people who were able to connect with her – her maid Nagamma and her friend Rama. Although, it would seem as though they were not talking to her directly. They would talk about things around her and suddenly she would respond. She seemed to like their company. From my side, I was not sure where I had to go for help from here.

I was losing my child. I asked the God above for help, who I felt was testing me. I could not look her in the face because this distant look in Babli's eyes made me feel helpless. The exact words I wrote that day were as follows.

'I feel tired and let down. No one is able to point out why Babli is lost. Some say she exhibits symptoms of autism, while many psychiatrists still say she cannot be depressed as people with Down syndrome cannot get depression. There are so many people who look at me as if I have not been a good mother and I have not given her more time. Where do I go for help? My own baby does not seem to love me.'

Guilt started building up within me. I started questioning my own methods of motherhood. What did I do wrong? Was she on too many vitamins? Would this be the way she always would be? Is she going away from us? Is this God's way of punishing me and her, but for what? This and many more questions revolved around me as I saw Babli becoming more and more introverted. I'd had appendicitis surgery, which seemed to keep me tired all day and I was unable to see my baby the way she was now. Her birthday was coming closer and we were all trying to involve her in the celebrations that we had planned.

4 January 2000

Babli was showing a lot of affection and her behaviour seemed more normal than it had been in a long time. The previous night, she had been very communicative. She sat with us at the table and was in a good mood. She joined in the conversation and sang and hummed like the old times. She even served herself. When we went to her room to try on her new clothes however, she refused to allow us in and went to put on her nightdress. We found it adorable that our old Babli was back and I cannot say how relieved we all were to have her with us the way we knew her.

5 March 2000

Sometimes good, sometimes moody – I felt she was not interested in making contact with anyone. However there were times when she would come around by herself. In school she would speak to Rebecca (her special educator) but most times she would drift away.

One day I was sitting by myself having closed my eyes since they felt tired and Babli's first thought was that I was crying. She immediately pulled my hands away and asked me not to do that. She would get terribly upset if she thought I was crying. What do I say to my child who does not want me to be hurt? Here I was bleeding inside because I was unable to comprehend and handle the problem that my baby had.

All the psychiatrists whom we met in the year 2000 insisted that Babli was a person with Down syndrome and this behaviour was normal. She was not expected to behave otherwise. But my point was that Babli was born with Down syndrome. It had not suddenly manifested itself. My child was born with Down syndrome and against all odds this child had outperformed many of her peers who did not have her condition. She was a fighter, an achiever, a gold medalist in swimming, a great dancer who spoke in three languages and could express herself fluently. This child was allowing everyone to push her over. However, at this stage, she was not even aware of where she was and this was killing me.



26 March – 1 April 2000

Despite how I felt, I decided to take her to London to see if there would be any changes in her behaviour. I was hoping that a change in environment would be able to bring about some change in her attitude and her behaviour. I would not deny that there was a lot of apprehension about her quick temperamental changes and yes, Rahul and I would feel threatened by crowds and airports because of long queues, yet we decided to take a chance. My only positive point of contact was Rahul. I felt so confident with him around, it was like he was my life line.

Unbelievable but true - Babli was a gem on the flight and never gave us any anxious moments. She not only spoke coherently but very sensibly too. She tried not to talk to herself and very politely and clearly asked for soup from the air hostess. An incident that brought a smile to my face happened when during the flight, she saw her father discussing business with Rahul. She suddenly looked at him and asked "Why this bout of affection for your son?," to a surprised father and brother! When my niece, Meghana, walked to the first class cabin she wanted to know from her where she had been that long. The kind of coherence she displayed on the flight was heartwarming.

15 April 2000

After a lot of discussions and after giving her Eltroxin (a drug used for underactive thyroid, to help maintain normal mental and physical health) for nearly nine months and finding her still having mood disorders, it was decided that we took her back to Doctor Rangarajan at the Malar hospital. We also consulted Doctor Natarajan and our nephew Doctor Navin in New Zealand, who is a psychiatrist. Based on their recommendation, we decided to put Babli on anti-depressants.

Doctor Rangarajan said, "*All medicines have side effects, so it's important to have regular follow ups with the treating doctor to assess and treat any adverse effect of the medicines.*"

Zyprexa 2.5mg. We were told that the drug might have some side effects like drowsiness and some of unsteady movements. We also checked with other doctors who agreed on the dosage and asked us to keep her under observation. It was a week and we noticed visible changes in her. Our Babli spoke very well to Uma and Paddu (one of Babli's friends) in Besant Nagar. And when she had an argument, she spoke in her usual authoritative way. It was heartening to note that all our friends commented on the changes in Babli who seemed better and was responding well to the medication. We also had to start increasing her food intake slowly since her appe-

-tite seemed to be getting better. By this time, her weight had come down to 38kgs and she looked drawn and weak.

23 April 2000

Babli slept a little longer than usual and seemed a little dull-towards the end of the day. However the good thing was that she definitely seemed better and spoke more. We all noticed visible signs of improvement, but there were also very low moods. After a week we met Dr Rangarajan and she threw a tantrum. She even slapped the doctor. But remorse set in and she was terribly apologetic and kept apologizing to Rama and me for her rude behaviour, almost as if she was aware she wasn't acting in the way she wanted to, but didn't want to admit it.

It was not that she was always her old cheery self. There were still days of long silences when she would not like being disturbed at all. She would refuse to speak to anyone and continued to turn her face away, asking me to get out or shut up.

28 April 2000

We continued Babli on the same dosage of Zyprexa and Doctor Rangarajan came home to check Babli in her family environment. She was good to him and answered all his questions. During this period, I made a trip to Delhi. Babli seemed to have missed me because over the phone she said "Mom come back quickly." This was one good sign that she was getting back into her old groove.

The previous day, my husband (Rami) had hurt his foot when he entered the room. He sat next to her and mentioned to her that his foot was hurting. She looked at him and said "If you had watched where you are walking you would not get hurt". She now seemed to get close to her old self, making intelligent repartees and being assertive, but she was still a far way off being the Babli of old. She also would display some antisocial behaviour at times. But overall, we could detect some improvement in her.

When my cousin Rama came in from Hyderabad with her two daughters, she was definitely very polite to them. Another sign of the good old times. However, she would sometimes look and feel very tired.

One noticeable thing about Babli during this period was her craving for sweets; her appetite was not only improving, she had also started to ask for sweets which she previously has not seen or tasted at all. She seemed hungry for rice and curds and sweets especially gulab jamun. All of us were definitely happy with her improve-

ment and we thanked God that she had started connecting with us again. Changes we had all noticed in 15 days at this time:

- Eye contact was better.
- Face was brighter.
- Eyes had expression.
- Had an appetite and was actually demanding food.
- Slept longer and more comfortably.
- Seemed rested and relaxed.
- Asked questions.
- Answered all questions immediately.
- Seemed to have gotten back her sense of humour.

(The below anecdotes happened between March – April 2000)

No Pushover

There's a perception that people with Down syndrome are faint-hearted and easily intimidated. But this is just a perception. Just because they have Down syndrome doesn't mean they can't be strong willed and know what they want. Here's a couple of examples to reinforce this.

On this occasion, we were travelling to London. Babli was in cracking form from the time we left the house and right the way throughout the flight. She was polite, on good terms with everyone and was on her best behaviour. As we got off at Heathrow and were walking out, at some point, her father tugged at her and said "Walk fast Babli". That was it! She just plonked herself down on the floor at the airport and refused to let anyone of us go near her. Her father apologized, her brother offered to piggyback her, I offered to take her along with me, but to no avail. Anyone went near her and she would scream her lungs out. People at the airport probably believed that we were tormenting the poor child. Babli sat like that for about an hour and a half. Finally she said "OK, I am ready to leave now!" And people with Down syndrome are supposed to be timid and easily intimidated?

The profuse apologies from her father and the cajoling by her brother and I was all in vain. At that point she proved to us that she was not some shrinking violet of a child who could be easily pushed about. The message without was clear. "I'm an adult. Treat me like one."



Another time, Babli demonstrated her very protective streak for her brother. We had gone to a fine dining restaurant on our trip to Switzerland where food, in these types of restaurants, is often served with a silver dome on top of the plate. When Rahul's plate arrived, Babli jumped up and refused to let him pull up the dome, saying there was something underneath which could threaten his life. Although highly amusing, we didn't want to patronise her, but instead recognised her act of love and bravery towards her brother. With or without Down syndrome, her character shone through. She showed the strength of character to speak up in public when she had perceived a threat. Not many people would do that. We have obviously guided her in future situations where she has sensed a threatening situation, but the bottom line is she has a good streak of courage to her.

May 6 2000

Babli was extremely receptive until she saw Rahul and she immediately called up Rama and asked her to come home by auto. She laughed her usual throaty laugh when I yelled at Rami. She seemed like her old self and insisted on Usha staying, eating with her and then leaving.

6 June 2000

School reopened and she was happy to be in class. Babli had definitely come a long way. She had again gone back to being her bubbly old self and was very sarcastic. She had returned to her routine and attended classes at the centre and would then go for a swim. She seemed to like drinking a Coke now and then. The point was that she was asking for all this without being offered or even our mentioning it. Very positive. On the way back from the beach house she drank the whole can of Coke, something she had never done before. That evening she went up to her father and insisted on going out to dinner with Rama for which she collected 1000 Rupees. On her way out she wanted to know if we had fixed an appointment with the actor Ravi. Nizhalgal Ravi, the actor whom she wanted to meet, came home at our request to see Babli and of course she was ecstatic. The whole day she seemed on cloud nine and she just smiled all the time. To Ravi she gave vent to her feelings and sat close to him as though he was her good friend. We felt she had come a long way since June 1999 and her weight was now a healthy 46 kgs.

In school her responses seemed much better and all the teachers commented on the favorable improvements in her. She started to participate in dance and other activities that she had shunned for such a long time. The biggest improvement that we noticed and that gladdened us was the fact that Babli had now gotten back her throaty, loud and infectious laugh. It was loud as it had been and was now in the right context.

The doctors had finally hit on the diagnosis for Babli's condition - psychotic depression, also known as depressive psychosis. The condition tends to occur within the spectrum of bipolar or a major depressive disorder. Those who have severe clinical depression may experience hallucinations and delusions, and they are also said to have psychotic depression.

Some of the symptoms I'd experienced with Babli that reflected psychotic depression:

- Struggling with a skill base that would previously have been easy.
- Varying behavior.
- Speech repetition.
- Anxiety and fear.
- Loss of appetite.
- Issues with consistent sleep.
- Loss of speaking ability and a general reduction in engaging in conversation.
- Losing eye contact.

We had appointed a clinical psychologist to do her assessment on a regular basis, who came out with the Wechsler's Intelligence Scale (children's version). She seemed to have progressed very well and both Rama and Sundari (our maid at home) saw the changes. Everything seemed to be going well except that her appetite was increasing at a very rapid rate. We were also having only one major health issue - we noticed that Babli's eyeballs were rolling up. On hearing about the rolling up of the eyeballs, Doctor Navin, my nephew, felt that it would be better if we gave her Pacitane 1 mg, to fight off the effect of the Oleanz, another drug that we were giving Babli. At this stage, the reality was, we were still in the experimentation phase of testing the effects of drugs on her condition.

9 October – 26 October 2000

In June we took her to London to check her eye sight and to understand why her eyeballs were moving up and down. I had a feeling that it was because of the dosage of anti-depressants. After that, it occurred to me that it was perhaps due to Babli's major eye surgeries, which had made her eye muscles weak. In London they were surprised as the power in her eyes seemed to have improved. She was focusing and seeing things better and was even able to read fine print. So why were her eye balls going up so often? Was she tired? Were her eyes reacting this way because of nystagmus (a condition primarily associated with involuntary eye movement)? As a mother we tend to imagine the worst. Every time it would happen late in the evening and we would call up the psychiatrist. He would then recommend a cup of coffee or cocoa to act as a stimulant.

Sometimes it helped and at other times it remained the same. We continued to pass one day at a time and made the best of it.

November 2000

Six months after we had started giving her the Zyprexa we had the same old Babli back with us. She was now talking more, relating more, was happy and taking part in all activities at the centre. However; she started gaining weight and would eat lot more food, especially rice and milk sweets.

We decided to keep her on Pacitane 1mg with Zyprexa 2.5mg with an interval of three hours. She continued on Eltroxin for hypothyroidism in the morning.

We also did an EEG on the advice of Doctor Biswakumar the neurologist and thankfully, the results were normal. All the other parameters were perfect and this situation continued for two years.

January 2003

Babli was 50 kgs and it frightened us that she would become too obese to walk. So we consulted Doctor Rangarajan and he asked us to discontinue the Zyprexa but continue the Pacitane twice a day.



10 March 2003

We discontinued all the medication for depression but we were asked to continue Eltroxin early in the morning. She was doing well but her interests became focused solely on certain areas -education was not one of them. She opened a shop in school and sold tea, cookies, pickles, juices and jams. She would still tape music for her friends.

23 March 2003

Two months after discontinuing medication, Babli's weight stood at 42 kgs and we were very happy with a lot of physical developments, which included:

- Loss of weight.
- Thicker hair.
- Clearer skin.
- Better gait.
- She walked on the treadmill for 20 minutes in the morning and swam for an hour in the evening.
- Appetite was under control.
- Doing well at home and in school.
- She had a strong like and dislike of people. She could not be convinced to adjust or act. Her character was positively strong.

The psychiatrist advised us that she should be left alone when she wanted to be, which made total sense.

What we realized through this phase was that early diagnosis and proper treatment is compulsory for a person with Down syndrome. We were lucky to have understood it and stood by Babli during her trying times. Yes - people with Down syndrome do get depressed! They need our help and care during their trying times. We need to hold their hands and help them cross this phase. We can and we should!

Doctor Rangarajan said:

"It is wrong to say people with Down syndrome cannot experience any psychiatric disorder. It is important to have a complete assessment by a physician, a neurologist and a psychiatrist in order to properly define a persistent behavioural and emotional change. This will help immensely in arriving at an accurate diagnosis and in planning treatment."

Time passed and it was almost five years since Babli's first episode of depression. We started seeing some of the old symptoms in Babli and we went back to our doctor.

28 July 2005

We had a discussion with Doctor Navin Rajan and had treatment by Doctor Ranganathan.

Doctor Navin was very clear that Babli was bipolar and definitely psychotic. He asked us to increase the dosage of Quetiapine to 200 mg/on 28 July. I spoke to the doctor and he felt that we were ignoring her psychotic condition. For some time we had been giving her Quetiapine 25mg at night. He asked us to increase it every alternate day by 25mg.

29 July 2005

We gave her an increased dosage of 50mg and she seemed a little better the following day.

2 August 2005

When I returned from Kuala Lumpur, she seemed very distant again. I immediately raised this issue with Doctor Navin who felt that her closeness to the Supreme Power (God), hearing voices and being scared were all absolutely normal in her present state of mind. He asked us not to make an issue of the voices and not to discourage her or fight her. We were asked to play along as her imagination went wild and accept her present state of mind. We had increased Quetiapine to 75 mg and Babli was talking more sense and she seemed more aware of her surroundings.

Medication Dosage of Quetiapine

(N.B – each individual has their own medical needs. Please do not look at the below as a prescription for anybody you know with depression. Ensure they are recommended medicines by a professional consultant for their individual needs. Also, it's certainly worth remembering the merits of non-drug interventions. Support in the form of talk therapy, support groups, exercise, and healthy living can make a remarkable difference, even (or especially) for severe depression.)

Date	Dosage of Queitipine
July 28, 2005	50 mg
August 2, 2005	75 mg
August 4, 2005	75 mg
August 5 & 6, 2005	75 mg

By this time, we also noticed that Babli was sleeping more peacefully and also appeared happier. She was responding to questions and appeared less distracted. Sometimes she smiled but at the same time could be a little jumpy and restless. She expressed something that made us happy – that she felt a lot happier these days. She even gave her maid (Kala) a ring which she said she had given to Kala with “lots of love.”

8 August 2005

Babli was oscillating between high and low moods. At times she seemed to have been weeping. By evening her spirits had lifted up once more and she was in a better frame of mind. However, she had come to the conclusion that there had been a puja in the house that morning and that all of us had lied to her about or kept it a secret from her. Because of this, she actually called me a liar and pounced on me. Then she started crying loudly. She asked me to kill her and she looked manic. Her expression was horrifying and she cried from the bottom of her heart. It was absolutely heart wrenching to watch. This was too much for me to take and so I checked with Doctor Rangarajan about this episode. He advised that we increase the dosage of Queitipine to 100mg.

The next morning when I asked Babli if she felt better, she smiled and told me that she was feeling happy. Her face looked relaxed and throughout that day, she was happy and connected.

We had to take her for a blood test as Doctor Navin wanted to keep a check on her plasma Levels, Iron binding, secretin, liver functioning and routine blood analysis.

9-10 August 2005

Things went off smoothly with no hitch and she seemed to be completely in tune with the present. The feedback from my sister and Rama were fairly good. On the morning of 11 August however, she appeared restless and an inherent fear pervaded Babli. My sister Lakshmi felt that she was crying and seemed frightened of some unknown factor.

12 August 2005

Babli's constant refrain was that God did not love her. She was constantly complaining to my sister about me and to me about her. Rahul came in order to cheer her up and spend some time with her, but she was lost in her own distant world. Many times Babli seemed irritated when she thought of us as intruders who were trying to enter her thoughts. She preferred to be left alone, as she was talking or relating to someone else in the world she had created for herself. She did not want to get out of her room and she would sit there and keep repeating that she was afraid of dying. This deep fear of an unknown entity – either living or non-living was starting to get worse and she would keep repeating "Bhayam" – Tamil for fear. All of us at home tried to amuse her by involving ourselves in games and other activities but she got annoyed with all of us. Nothing seemed to be working. We decided to call Doctor Rangarajan who advised us to increase the dosage to 200 mg that very day. Since we were worried about the side effects, he assured us that the only symptom that we would have to deal with was drowsiness.

13 August 2005

Babli was definitely happier. The day passed uneventfully and she was planning to go and spend the day with Uma in Besant Nagar. There was this constant nagging doubt in her mind whether God loved her or not. She wanted to know if she had 'bhakti' (devotion) or not. But on the whole she seemed to respond well to her surroundings. In the evening she went to the temple and seemed peaceful.

14 August 2005

Rather uneventful day. She seemed at peace.



I was losing my child and had no one to help me....the God above seemed to be testing me.....This far distant look in her eyes made me helpless. I could not look her in her face.. I was unable to help!!!!

15 August 2005

The morning was good for her and she danced fairly well in class. By evening however, she created a huge scene wanting to visit a temple, and we were forced to comply as symptoms of anger and withdrawal were building up. Having seen her normal for a few days, we were averse to having her lapse into a discordant mood once again. Just a few minutes at the temple and she became happier and more connected.

By 6pm her mood had changed once again. She started crying after watching the tape of her Singapore visit and Sandhya on T.V. This change in mood is what bothered me the most. Her constant refrain was always about her relationship with God - whether God loved her, whether she had bhakti, if God would punish her. It was absolutely heart wrenching. This constant questioning by her was shaking my faith, wanting me to believe that there was no God. And when we asked her a question it either did not register or she was talking to someone else and disliked us interrupting her thought process.

16 August 2005

A pretty ordinary day by all counts. She went to Besant Nagar, and seemed happy. After that she came back and played on the keyboard and went to the temple.

17-18 August 2005

She seemed fairly stable. Crying was in smaller spells and was controllable.

20 August 2005

Doctor Raja came to our home and he sat with her for an hour of counseling. His assessment took some time as she was telling him about her five fathers and five mothers. She was definitely on a high for an hour. Just as he was leaving, she started looking sad. We were not sure whether it had anything to do with the doctor's visit. She then explained the reason for her sadness - we had asked her to take "her" money for the temple and "not from the goddess mother", which she found very insulting. According to her, we had passed a sentence saying her godmother had no money and that upset her. In addition, the hot chocolate that we gave her that day had no froth (she liked her hot chocolate frothy) and that upset her even more.

Dosage as of 20th August

1200 mg Oxcarbine (primarily an anticonvulsant drug, but also helps with mood stabilization).

Time	Dosage of Oxcarbine
9AM	300mg
2PM	300mg
9PM	600mg
Time	Dosage of Queitipine
9AM	250 mg
12PM	250 mg
9PM	200 mg

21 August 2005

The day began on a bad note. Babli started the day crying on the treadmill. When we asked her what was bothering her, she would not tell anybody. Finally she complained to Rama that God had spoken to her told her that she had not really slapped Kala but had just tapped her. She made it a point to let her know this and of that she was very clear. She spent the rest of the day in Uma's house and the day went on without any further hitches. In the evening after she came home she started saying she was scared and she called Rama and said she was feeling very scared. In order to cheer her, Sundari gave her one of her favorite sweets – payasam. This helped and Babli seemed to touch base with her normal self and all the fear seemed to vanish. She was back to normal. Rahul went to her room a little later and she asked him to go upstairs to his room as she was watching her favorite serial - The Mahabharatam.

21 August 2005

She seemed more calm, controlled and talked to everyone. In order to retain this state for Babli, Rama tried to amuse her by playing movie songs on the T.V. At this, she wanted to know why she was allowed to watch T.V. and was not being made to study?



Save me Rama Aunty, I do not love anyone any more.....I want to go away. Help me!!

23 August 2005

This was a bad day and she refused to go either to Rama's or Lakshmi's house. She got her periods and seemed bad-tempered. She wanted to go out for a hot chocolate, to which I promptly agreed, since I wanted her to get back to normal at the earliest. I asked her to go to Qwiky's, a really nice coffee shop. On the way she did stop at Ramas house but refused to get out of the car. She took Lakshmi with her in the car and then got off at her place. At 4pm she came home and seemed disturbed and sad. After half an hour her face puckered up and she dissolved into tears. Her crying started as a low intermittent sob, after which she cried inconsolably for more than an hour.

Her crying mood continued for a little longer than it normally used to, but finally she stopped and played her music which lifted her spirits. At 7pm she wanted to watch a God film, one of her favorites - Nam Veetu Deivam (God of our house). After watching the movie, she said she was again scared that God did not love her. She began to have doubts regarding her bhakti. Since she seemed so disconsolate, I called Doctor Rangarajan and he asked me to include Zyprexa 2.5 mg along with her medicines.

24 August 2005

She went back to her own world, seemed very distant and kept picking on people wherever she went. She met Dushyant (Rani's grandson) and accused him of not having any bhakti. The whole day, she seemed ready to pounce on most of the people she met at various times of the day. Only by evening did she seem slightly better, and when she met Usha her other friend she talked continuously as if she had to catch up on old times. She insisted on telling her that she had many fathers and mothers and told her that she had visited a number of temples. On the way to Grand Sweets (afantastic sweet shop), Usha mentioned that she had only one father and mother and that upset Babli to such an extent that she started wailing again and that continued for over an hour. On hearing about how upset Babli was, Usha called to apologize, but she refused to speak to Usha. Immediately after this, Babli had her dance class and amazingly she did so well that Shritika, her dance teacher, called to tell us that Babli's performance was superb and she had made no mistakes. It was commendable that music and dance, which were given to her as alternative therapies, were keeping her sane.

On the 25 August, Babli was so good that everyone noticed and commented on the change and she was receptive and also reciprocal. Not once did she make all those neighing sounds or sounded distant. Thank God for a good day.

26 August 2005 – 30 December 2005

She seemed happier and more responsive. She went about doing her jobs and going to temples. There were no complaints from either her teachers or from Lakshmi or Rama. Yes the doubt still would come to her mind whether God actually loves her. But she found a way to assuage this fear - she would ask people, especially Rama and conclude that God really did love her. For the annual day, she agreed to participate and was prepared to dance with all the other members in Mathru Mandir. She came to practice regularly and was friendly and polite with all the children and adults at the centre. She not only came to the centre but also made polite conversation with all the staff. She would answer all their questions directly and coherently. She followed all the dance instructions without a hitch and it made us all very happy to have her back in the centre of all these activities and participate with all gusto for these events,

For me personally, I was ecstatic that my little one who had lost her direction, all her bearings was now back and raring to go. For a while I too had thought it was a lost case and I thought Babli would never come back from her world. But her homecoming can be attributed to the honest and earnest support of all my friends especially Rama, Lakshmi, Sundari, Uma, Rahul and the constant support of the psychiatrist Doctor Navin and Doctor Rangarajan. I send my heartfelt thanks to the Lord above who helped in bringing my lovable happy child back to this world, back to me.

Medication as on 27 January 2006

Oxcarbine	Time
300 mg	9 AM
300 mg	2 PM
600 mg	9 PM

Queitipine	Time
25 mg	12 PM
2X100 mg	7 PM
0.5 mg Zyprexa	2 PM

April 2006

Things seemed to settle down after we introduced the Zyprexa and she was very happy and she showed her intelligence at every occasion. Her dance performance at Kalakshetra and her tuning in with noted singer Shri O.S. Arun and the dancers was indeed a memorable stage in her and our lives.

The first week of March, we took the advice of the Psychiatrist and we took one 300mg Oxcarbine and a 100 mg Queitipine off her medication list.

Towards the end of March we took her off the Zyprexa and the dosage there was :

Oxcarbine	Time
300 mg	9 AM
300 mg	12 PM
300 mg	7 PM

Queitipine	Time
25 mg	12 PM
100 mg	9 PM

April 10, she was again a little insecure and we called Doctor Rangarajan and he asked us to increase the dosage of Queitipine from 125 mg to 150 mg.

26 January 2008

All seems well. Babli turned 27 years old and was on top of the world. She had become expressive and more talkative. Her cognition skills had also become much higher. She was still on what she called the happy pills and with her experiences; she can be considered the true guide for all people who face depression in Down syndrome.

She never complained and started feeling blessed and until this day thanks God each day for her existence. Her belief in the almighty has been strong and unshakeable and she continues to be the joy of our family. But for her our family might never have lasted all these years of tension and stress that depression had brought on to us.



Chapter 5.....

REFLECTIONS ON BABLI'S EPIC JOURNEY OF DEPRESSION

You've read through my eyes what Babli was going through, but I believe there are also merits in taking a moment to read from others who were also close to Babli during her time of need.....

What Babli's friends and carers had to say:

A few words from Rama (Babli's close friend and confidant), reflecting on Babli during her time of depression.

Depression is a mood disorder that can take the joy from an individual's life. When Babli was going through that I spent a lot of time with her, really not knowing what depression was or what she was going through. She was blank and I was ignorant. That's a 'minus X minus.' Equation, but somehow, equaled a plus, as our friendship grew up very well during this time

Babli used to have severe mood swings and used to get angry very fast. If I tried to engage her in any conversation, but she would give totally irrelevant answers. She used to keep saying I am afraid I am afraid. Her eyes would be dull always and she would be just staring without really focusing. Sometimes she will suddenly cry. Most of the time her eyes will be with tears and if I ask her why she is crying the reply will be "Theriyalaye", I don't know.

Many times she used to tell me "Amman is speaking to me" and asking me to do this or that." It was like she heard inner voices. Her belief in God was immense. She loved listening to music and would be in a kind of trance when music was played.

That phase of Babli's life is over and I pray to God it never ever occurs again. She is a Bubby and vibrant person now and I hope she remains like this always.

A few words from Vasanthi (One of Babli's carers)

I have known Babli for 14 years. When I first met her, she came across as an insecure and very rude individual. She was possessive of her mother and her relationships with others around her, perceiving me as a threat to the attention she was receiving from them. She suffered bouts of anxiety and depression and it was very difficult to communicate with her on any level. When those around me shared that Babli was a sweet, friendly and happy individual, I wondered if they were speaking about the same person. Gradually, over time and with inputs both psychological and medical, I saw Babli transform. She became more approachable, started relating to me as an ally, was friendlier by the day and slowly established a wonderful equation of love and trust with me. I also found that she had many talents – she began to dance, started Vedic chanting and yoga and also became an excellent swimmer. Today, her earlier behaviour seems like a distant memory to all of us and true to her name we have amidst us a “Bubbly Babli”. I have realized in my interactions with those with Down syndrome that they can go through patches of psychological ill being, but with appropriate and timely treatment, can become well and can adjust quickly.



Chapter 6.....

LIVING WITH A DEPRESSED LOVED ONE

*A*lthough a person with depression, at times, may seem to cope well, what you see is only one side of the story. For example, if you have a sprained ankle, anything you do on it hurts, but that cannot stop you from taking care of some things in your life. So you rest when you can and endure the pain when you must. The illness stops them from making healthy choices, affects their judgment, and dashes their hope. While your sprained ankle will get better more or less on its own, depression without intervention, can feed on itself and only get worse.

Here's a few recommendations purely based on my experience with Babli:

- Listen to the person, while being sympathetic, affectionate and appreciating them. Simply by spending time with them will in itself help them to get better. Losing your temper or being irritated is a definite no-no, because they are highly sensitive at this time. They are already frustrated with seeing no exit route to their state of mind. If you demonstrate further negativity, this will send them further down the slide. This is when you need to interact with them as much as possible, even when what they are saying may not make logical sense. Ride the storm with them so to say. Listen when they talk, don't press them if they don't want to and be considerate of their feelings. Make a few allowances, especially in the beginning. If they behave inappropriately, tell them but politely. The only treatment they need is not being forced into situations they find stressful. They need what everyone does - courtesy, kindness, and constructive feedback.
- Don't blame the person for being depressed. Do not tell them to 'relax' or 'calm down'. They are probably already blaming themselves and criticism will make them feel even worse.
- Someone with depression may get irritable and be more liable to misunderstand others, or feel misunderstood, than usual; they may need reassurance in some situations, and you will need to be patient with them.
- Remember, treatment will take some time to take effect, and make them feel better. So be patient and wait for them to feel better.

- If your friend or relative is severely depressed, you may be faced with some hard decisions about how much to do on their behalf. If, for example, they are not looking after their physical needs, should you take over and do that? A therapist, who knows the patient and who knows what he or she requires would be the best solution.
- Throughout this withdrawal period, be watchful for danger and suicidal signs. Respect their feelings and them as a person. They are ailing, not unintelligent. Interact with them as you would with anyone else. Reinforce normal for them because all they want is to be “normal”. Feelings of hopelessness, helplessness and worthlessness are a major part of depression. This can make someone avoid their friends and relatives, rather than asking for help or support. Remember, this is when they need your help and support the most. At one stage, Babli looked at me for days trying to explain that she wanted ‘normal’, and could not understand why a mother who had always taken away the pain was not doing something for her. That was heartbreaking to listen to and made me feel helpless.
- Very important – look after yourself. Supporting a friend or relative who is depressed can be an opportunity to build a closer and more satisfying relationship. However, it can also be hard work and frustrating, at times. Unless you pay attention to your own needs, it can make you feel depressed. It's important to remember that you should be taking your own advice. In the same way you are telling the person with depression not to be afraid of opening up about their illness, you should also be aware that you are not fireproof. You may not be able to offer that 24/7 care. If you do, you may will start to deteriorate both mentally and physically. In order for you to offer the best of you, you need to recharge. There's a reason why organisations have 9-5 shifts. Work more than eight hours and the caliber of your work starts to deteriorate. The same applies with caring. You need those breaks. Try and get others involved to dilute your pressure and stress. There may also be a local support group of others in your situation. You could also talk to your GP or another healthcare professional about getting help for yourself and your family.

So - this is my mine and Babli's story. A tale which some may have empathy with, either as a parent, a sibling or a person with a mental health condition. For others, my story will provide an insight into the pain and destruction which falls into the slipstream of depression. I'd also like to think that by the time you come to the end of this tale, you will also find some solace. By no means am I offering solutions with my story – more an insight. If even just a handful of people are able to take something positive from this, then it was worth me sharing the story, purely on those grounds.

CASE STUDY

(Based in London, UK)

This is the story of Bashir, a 23 year old man with mosaic Down syndrome. The tale is carefully narrated by father Ally and demonstrates again, the struggles which come with dual diagnosis and the essential intervention of qualified assistance when discovering a mental health condition is apparent. We thank Bashir and his family for taking the time to share their experience.

When Bashir was born, he was not diagnosed with Down syndrome (DS). It wasn't until eight months later when we went along to the doctor for the normal check-ups. The GP picked up on certain things, like the way he was sitting and a few other things and referred us to a consultant.

After conducting some tests, the results came back that he had mosaic Down syndrome. Because he is mosaic, his (DS) features were not very obvious, which was why this was perhaps not picked up on sooner. Thankfully, we had a good consultant who gave us some good advice and relevant materials, such as a leaflet for the DSA (Down's Syndrome Association, UK).

Ever since we found out he had DS, we treated him no different than anyone else. Initially, yes, I was sad at the news, but then I flipped it and moved forward in a positive way. I decided to understand exactly what Down syndrome was. Like many, I'd heard of the condition before, but didn't really know what it was truly about. So I went to the DSA and that was the best thing I did. We started to read stories of people with DS doing well and living semi-independent lives, which gave us something positive to look forward to. We were also given the details of a lady who was a big support to us, an inspiration. Her name is Ellen Goody. To see someone else with DS who was genuinely living a life was a massive inspiration. It wasn't all doom and gloom for us.

At the age of four, I also noticed that my son had autistic tendencies. I mentioned to the medical professionals at the time, but they ruled that out, so we had a battle on our hands to prove that he was on the autistic spectrum and needed relevant support to cope with this. My son was quite sociable and they basically said, 'If someone is sociable, they cannot be autistic.' That was their approach at the time.

That made it very difficult for us to understand and when he started going to school, his autistic tendencies were looked at as him simply being difficult or naughty. He was even given detentions for this, which is crazy. At that time, the way it worked was, your child would go to a mainstream school with special support, but unfortunately that wasn't always great. They're was a long waiting list for speech therapy, physiotherapy etc. We had to fight the system.

By 2009, Bashir was 15 years old and attending a mainstream secondary school. He was in his final year and was enrolled for the ASDAN certificate (A certificate which would offer a qualification to show competency skills in learning, life skills and skills for work). With a certificate on the horizon, Bashir was looking forward to progressing to college after leaving school.

Then something happened. An event which changed Bashir's life, and mine and my wife's. Bashir started to get bullied by one of his 'friends.' He came home and was confident enough to tell me and my wife about the episode and I consequently contacted the school to look into it.

The response from the school was useless. 'Oh no. It wasn't like that, it was something else. He was fine and he's had a good day,' they would say. If someone sits down in a class, doesn't speak to anyone or want to participate in any activities, is that a 'good day?' At the time, Bashir had one to one support, but it was very hit and miss. Because of that he was open to be bullied.

The school continued to deny the occurrence of the bullying and over time, he became depressed. It was my son's word against the bully's word and due to a lack of witnesses, no attention was given to further investigating. The fact that he had a learning disability was an easy scapegoat for the teachers to say that it was all down to that. My son stopped eating, refused to go to school and not participate in anything. He shut himself down. The local professional failed to realise that something had happened to my son. Because he was 15 at the time, they put it down to adolescence and apparently this behaviour was part of that growing up process. Really?

From that day onwards, Bashir changed. We kind of lost the version of Bashir we had known for the last 15 years. Mentally, he never fully recovered from the bullying episodes and continued to get flashbacks and nightmares. These were obvious post traumatic stress disorder (PTSD) symptoms. He started to go to bed late, didn't want to eat and didn't want to go to school. For nearly six months we forced him to go back to school and at the same time had the local authorities threatening to take us to court if he didn't attend.

Despite the doctors sweeping his symptoms under the carpet with a diagnosis of adolescence, Bashir's situation did not improve. I even started to video him, just show the professionals his traits and how he was changing, but some, refused to watch them claiming they didn't need to.

Social services finally promised to do an assessment in September 2009, but again, nothing happened. No one recognised how distressed Bashir was after the bullying incident. He was not offered any counselling after the incident because no one really believed him. All they saw was a disability and put everything down to that. No therapies were offered. In the end, I sent a video clip and a private psychologist report to a specialist in America. He replied saying that these types of issues can be caused by trauma and if not treated urgently the damage could be irreversible.

By December, Bashir's condition had got worse and the local doctors took a decision with agreement from both social services and the LEA (Local Education Authority), to send me to the Coborn Adolescent Mental Centre for observation and to give respite to my parents.

I contacted the Down's Syndrome Association (National Office) who sent one of their representatives to support Bashir and I during a meeting. The local psychiatrist doctor was not very happy with that, because we came armed with knowledge. I declined their proposal and requested to be referred to a different specialist at the Maudsley Centre. We had to wait five months before we could see him because the PCT (Primary Care Trust) had to approve this.

By 2010, while we were waiting to see this specialist, Bashir's condition deteriorated and the previous doctor had removed him off his medication (Risperidone) which was not doing him much good anyway. By February 2010 me and my wife were so desperate to find out what was wrong with Bashir, that we decided to take him abroad for two weeks holiday. Once abroad we managed to see a doctor who told us that it would take a long assessment and treatment to find out what was wrong with him. However, he did recognise almost instantly, that Bashir was going through some child depression and trauma. He decided to prescribe medication for two weeks and asked me to get the doctors in the UK to continue with this and monitor.

But when we came back from holiday, the Doctors in the UK were not co-operative. Bashir's health got worse and I phoned the local psychiatrist who refused to do a home visit. She was too busy and asked me to bring Bashir over, which unfortunately was not an option as Bashir refused to cooperate. Uninterested, the

doctor said, 'If the situation got worse to take him to A & E.'

Unfortunately, his condition did get worse and I had to phone for an ambulance. As he was being a bit aggressive they came with a police escort, which was very traumatic for everyone, no more so than Bashir. They were not trained to deal with situations like this. He was scared and just wanted to go home. If the doctors had listened to my requests from several months before, I'm certain that events like this would not have unfolded.

Finally and without any choice, Bashir ended up at the Coborn Adolescent Mental Centre. He was scared stiff and was evidently very sad, as were we. He threw tantrum after tantrum and kept asking me to take him home, which was heart-breaking. He stayed as an in-patient for one week but then the doctors there decided to make him a day patient.

Incredibly, after asking me every conceivable question, which I gladly provided answers for, after four weeks they could not find anything wrong with him and discharged Bashir without any diagnosis. Bashir was still suffering and no one seemed to know what was causing his hurt. They were just talking about hormones or challenging behaviour. What utter nonsense.

Finally it was not until 2010 that we met a new doctor at the Maudsley Centre. As soon as he saw Bashir and interviewed me and Bashir's carer, he could see all the symptoms of autism, PTSD with psychotic features. How come none of the previous doctors could not see this? By this stage, the damage had been done to Bashir.

Bashir was born with a learning disability, but prior to depression, he did have a life. He used to go swimming, bowling, eating out in restaurants and visiting lots of other places. He used to make everyone laugh with his jokes and dances, loved watching television and listening to music. But today, you don't feel or see that happiness any more. If you were to see a video of him a few years ago and now, you'd think it was a different person. That's what mental illness does to you. His mental health has taken away a great deal of his capacity to express himself. But at least we have a little bit of him still alive. We just hope more of his old self can surface again.

At the moment we are trying to put him in a safe environment. For example, we are trying to find him a work placement, but he needs someone with him all the time. Before, at the age of 15, he never needed a personal carer. He was able to say which activities he wanted to do, when he was hungry and what he wanted to eat. Then after 2009, all that ability disappeared. It was no longer a case of having a child with DS, but having a child with a mental illness and trying to still make him part of society. That's the new challenge.

If you believe you're child or member of your family with DS has a mental health condition, it's very important to get a correct diagnosis early on. That speedy intervention is essential. Trust me, I've seen the destruction it's done to our family. The medical people and the social care team need to work together, very, very closely. If Bashir had been diagnosed earlier with depression, then half the problem would have been solved. Imagine – he's suffering at a place (school), and the advice is to go back there for more bullying, as opposed to taking him out of that place and reducing the trauma.

It's also important to ensure, as parents, you have support systems in place. It's essential for us to have respite care, in order for us to be able to offer the best of ourselves to our son. I became suicidal at the time when Bashir started to deteriorate. My wife had cancer a couple of years before Bashir's depression started and we don't have any other children. The pressure mounted up and there was nowhere to run. I was working full time and had to stop working to look after my wife and son. It was a bad situation, but the professionals did not see that bit. We needed 24 hour support and it was not forthcoming at the time.

I'd like to offer two pieces of advice. Firstly – if your child has DS and a mental health condition, it's essential to keep them active. If you don't, they will become a vegetable. It's very important for us to put Bashir in the community as much as possible. Interaction is essential. If you just stop being active, it's very difficult to re-engage in any activities again.

Secondly – Try not to get disheartened by professionals who try and sweep you under the carpet. Fight for a second opinion as much as you can. And if need be, if you have to spend your own money to get a private assessment done, then go for it. This is the life of a person at stake here. Network with other people. Contact all the relevant charities relating to your child's condition or illness and be in constant contact with them. There's not a lot of cases like mine around. Because of that, many professionals will see it as hard work.

Keep persisting until you find the right people and knowledge from people who genuinely care. Fight through the system and get what you are entitled to. Most importantly, never give up on your child.



THE BOOK



Depression in persons with Down syndrome is never discussed because it seems alien. However it is a fact that depression occurs among them too. This book looks into that phase of Babli, Dr. Surekha Ramachandran's daughter and her struggle with depression. It is a journey that affects the lives of all those who love Babli. It is a story of grit and determination and Babli's triumph over depression. It is a book which can be used as a guide for all parents who see their children undergoing depression and how to help them get out of it.

ABOUT DR. SUREKHA RAMACHANDRAN



Dr. Surekha Ramachandran is the Founder and President of the Down Syndrome Federation of India. Dr. Ramachandran has inspired many families to cope up with Down syndrome, with love and care. She has always emphasized the need for inclusive living for these individuals with Down syndrome. Her goal is to try and spread the message that Down syndrome is a genetic medical condition in which the person can come into inclusive living with early intervention and care.

"This book would not have been possible without the support of our editor Mr. Paul Zanon from the UK, who has taken great efforts to ensure that this book can be used as a guide for parents and carers of Persons with Down syndrome."



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