

World CML Day 2023

Child is the Father of Man

Spotlight on the children of our patients.
What it means to grow up with CML in the family



Artists Arjun and Firdaus

(FOM Pune)

Two young boys whose beloved uncle was diagnosed with CML found the care their uncle received akin to the protection the people facing the wrath of Indra received when Krishna held aloft Mt Govardhan over them.



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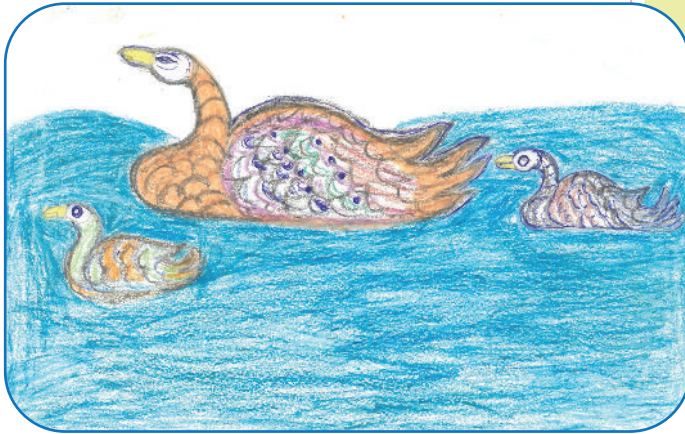
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"My father didn't tell me how to live. He lived and let me watch him do it."

Clarence Budington
Kelland



"The truth is that no matter how old we are, as long as our mothers are alive, we want our mother."

Goldie Hawn



"My heroes are and were my parents. I can't see having anyone else as my heroes."

Michael Jordan



From the Editor

How easy it is to take for granted what we have. The sunlight of the parental love we bask in, the unconditional love of mothers and the solid strength of a father's shoulders that can bear any weight with happy ease. No matter how modest the home and hearth, this makes it the richest place on earth. So, when a parent's life is threatened, can you imagine what goes through the child's mind? Can we imagine what it is to live with that threat looming over your beloved father or mother all the time; all of your growing years? The dark clouds of ill health shutting out the bright light that is life giving?

As we observe and celebrate one more World CML Day I wish to put the spotlight on some of the children who have had to see their mother or father being diagnosed with this potentially life-threatening condition and having to go on life long treatment.

It was a few months ago, at one of our Patient Support Group Meetings in Mumbai (held in Tata Memorial Hospital, June 2023) that I realised I was seeing quite a few young teenagers in the audience. They were very bright and energetic, participating with great enthusiasm in the interactive workshop and generally adding so much life to the proceedings. They looked a little familiar. It dawned on me gradually that they were accompanying a patient; either a mother or father and that I surely knew them from earlier encounters perhaps at the Max office or earlier meetings but now they had grown - not just in age but in their role and demeanour! From a bemused little son clutching tightly the corner of his mother's saree or hiding a tearful face in her father's tired shoulder to now confidently leading the very same parent by the hand into the meeting.

Looking at these young ones, William Wordsworth's line came to my mind - 'The child is the father of man'. How true it is indeed that the circumstances of a person's childhood go a long way in building his or her personality.

Presenting to our readers on behalf of The Max Foundation, Friends of Max and our patient groups in South Asia a glimpse into how, over two decades and more, the children of our patients have lived with their parents' CML.



- Viji Venkatesh,
Region Head, South Asia, The Max Foundation
Managing Trustee, Friends of Max

Meenu & Hari

Interviewed by **Sudha Samineni**

Meenu's son Hari was only ten when his mother was diagnosed with CML and his earliest memory is how when Meenu needed to go to the hospital to see her doctor, Hari and his little brother would be locked alone in the house because their father was an auto rickshaw driver whose daily earnings helped run the house. He could never take a day off. Whatever they needed during the day, including food, their mother would set out before she left the house and it was young Hari's responsibility to make sure his baby brother too was taken care of.

Is it any wonder he asks, that before he knew it he was as good a home maker as his mother was and neither his mother nor father needed to worry about anything other than their mother's wellbeing. Hari's mother's fear of dying made a deep impact on the young boy's mind and from then onwards it became his mission in life to never allow anything to frighten their mother.

In his own words: "Today after all these years I want to say something which I really love to say. My family and I are so thankful to my mother's doctor, Vrinda Kulkarni of Nair Hospital, The Max Foundation for her medicines and Ammaji and all the staff members of Max Foundation who work so hard to help families like us."

I have heard time and again from our patients and their caregivers how coming face to face with a life-threatening condition has completely changed their lives and, that too, only for the better. I met Hari after quite a long time at the patient gathering in Tata Hospital and saw for myself the truth in this statement and in the demeanour of this confident teenager. When he raised his hand to ask his question to the panel of medical experts it was with so much confidence and a heightened sense of responsibility and awareness. And looking at him listening to the response from the physicians with complete attention I said to myself, Meenu is in good hands.



Barun & Sanvika

Interviewed by **Komal Surve**

Eight year old Sanvika was born to Barun and Sangita when Barun had already been diagnosed and been living with CML for 10 years. Barun and Sangita's families had washed their hands off the young couple when Sangita refused to leave the side of her partner despite his diagnosis and her family's displeasure. They wanted them to annul the court marriage they had undergone and refused to bless their union socially. Barun and Sangita then abandoned all thoughts of settling in their home state of Bengal and returned to Mumbai where it became more and more difficult to make a living. Barun had lost his job in the jewellery store where he used to polish and set precious stones. It fell on Sangita's slender but strong shoulders - the responsibility of bringing home the means to run it. But there was no money for his treatment.

When Barun's treating physician guided them to The Max Foundation there finally came a ray hope in the lives of this incredibly courageous couple. Says Sangita, "In March 2009, we got to know about Dr. Ashish Mukherjee from another CML patient and he informed us about The Max Foundation. I submitted Barun's details and received a call from Amma. After that Barun started receiving his Glivec 400 mg medicine and our life again started blooming. In June 2011, we came back to Mumbai and started a new life."

Little Sanvika completed their joy. I remember visiting them on her first birthday and the happiness that enveloped their home was infectious. Today, this young girl makes them so proud by excelling in her school work. She sings, dances, creates the most beautiful art and tops her class year after academic year. She attends every single patient meeting with her parents (she was six months old when she attended the first) and is the first with her questions during the Medical Session. She is so very aware of her father's diagnosis as well his health management and asks the most pertinent of queries. All of us take her very seriously indeed - this primary caregiver to her proud father.



Rakesh & Aditya

Interviewed by **Prasad Kothekar**

A family that eats together stays together, right? When it comes to Rakesh Sharma's family, it seems to be this: A family that talks together survives together. Diagnosed when his children were seven and four years old and the youngest barely six months, Rakesh has lived with his CML for more than 30 years. He and his wife in this time, have cared for his mother, raised and married all the three children and lived a full, long social life; devoting time and energies to contributing to the community at large as well. I don't believe Rakesh has missed a single patient group meeting in his city no matter he lives in the distant suburbs and some of these meetings are the early morning ones in his beloved city Delhi's famed Lodhi Gardens. Nor has he missed a single All India or Leadership Summit. Accompanying him to every such meeting is Aditya, his youngest son, now 29 years old.

Rakesh has always been involved in community and social welfare activities, a frequent donor at blood donation camps before his CML days and a living example to his children of compassion and social responsibility. In fact, he has shared more than once how, he would make sure, as soon as it would be allowed, off he would rush to donate blood all over again.

Aditya tells us how he grew up seeing a father who never hid anything from anybody; was honest, upfront and fearless when it came to his cancer. "I, the youngest of all his children, have lived a life that has been daily inspired by this man my father who has instilled in me the greatest of ethics or values of life. I am the care giver for my father now and help my father in every activity that he is involved in. I am 29 and married and in my opinion, he has been an amazing example to me and the strongest father anyone could ever have. I have seen the times where he has displayed immense will power. We all three children have seen times where he has demonstrated the best way to face and live life to the best. And we

together have seen no time when he was feeling low or different because of this disease."

Aditya has only reiterated what his father has always held a firm belief in. That Strength is always in "WE" and not in "ME". As parents many times it is easy to underestimate the strength of children and feel overprotective of them. Aditya says his father never did that because he knew that would actually lower their morale and self confidence. Rakesh agrees, saying he never wanted any of his children to feel left out and not be part of any of the decision-making processes. Being together as a unit resulted in their cherishing both good and tough times as well as make them stronger individuals.

"Our father made sure nothing, least of all his cancer, came in the way of our well being. He provided us with what we needed the most to do well in life - the best education. It does not matter if we never did have some of the fancier things in life. With our parents' blessings we have all three found the best partners in life and have everything we need. Today I find myself in the position of being able to give back to Dad, to be his support and strength. His journey with cancer is still not over and I will help him by lending him a strong hand. The hand that he has strengthened with his love and courage."



Vir Krishan & Harshul

Interviewed by **Priyanka Kandalgaokar**

Vir Bhat, or Vir ji as we all fondly call him, I remember struggled a great deal initially to obtain treatment for his CML. Due to rather stringent medical criteria of the access program in its early days he had to purchase the really expensive medication for a while before he could be taken into the program. I remember him as someone with a great amount of suppressed energy, always mindful of not letting his emotions show, struggling all the while with the impact his situation had on his aged grandmother, his mother, his young wife and his five-year-old son who had just been admitted in First Grade. Perseverance indeed was his middle name and single handedly he navigated his way through the bewildering labyrinth of hospitals and consulting rooms of different physicians. I still remember vividly the day when almost 20 years ago Vir ji was finally able to qualify for the drug donation program. By that time i knew how much he had struggled to raise resources to be on the life saving medication - selling off whatever he owned and relying on support from family and friends. All the while he had his own family to take care of. Being away from his home up in Jammu for a long stretch of time he missed seeing his little son and had him brought to be with him. Looking at his innocent face and listening to his cheerful chatter about this and that all Vir ji remembers wanting is ten years of life so this baby boy could at least grow a little bit and take care of his mother.

That five-year-old boy today is a decorated officer in the Indian Navy: Lieutenant Harshul Bhat of the Special Forces and his father's pride and joy. Little Harshul for the longest time would accompany his parents to every single patient support group meeting and as Vir ji remembers. "I attended all the Friends of Max meetings along with my wife and child. Our son would distribute the reading material and would wear his name badge with great pride. By that time when he was in 8th Grade he understood a lot about the seriousness of my disease."

In Harshul's own words

"When the going gets tough the tough get going". I am a Lieutenant in the Indian Navy (Special Forces) and this is the proverb I read in the alleyways of my military academy which kept the cadets motivated. But for me this is what I had seen at my home since my childhood. I was in first grade when my father was diagnosed with CML. Though I was too young to understand the struggle my family was going through, as I grew up in that atmosphere, I understood what fighters my parents were. I always had this feeling of distress at the back of my mind about my father's health but even as a child I was comforted that The Max Foundation had held his hand. I also attended a few patient group meetings with my father and saw many children like me who had an ailing parent, sister or brother with them. We always say blood is thicker than water but here in my father's case, I saw friends and strangers helping us in a way even our own blood won't which proves the proverb wrong.

I never saw the fear of illness or death in his eyes and he was always the most cheerful in his group of friends which everyone appreciated. Hence that same qualities got imbibed in me as the apple doesn't fall away from the tree."



Param & Sangeeta

Interviewed by **Ashika Naik**

“My world which revolved around arts and crafts, solving puzzles, playing badminton, and watching cartoons soon became the life of a child whose parent has cancer.” Sangeeta, 29 today, was nine years old when her father, fondly called Param by all who know him, was diagnosed with CML. Param remembers vividly how as a patient he was told at the time of diagnosis this was the only cancer in the world at that time that could be treated with what came to be known as targeted therapy.

This was a ray of Hope especially after a futile attempt with homeopathy and alternative medicines failed miserably. Adding to the hope was the Patient Assistance Program from The Max Foundation which eased the considerable financial burden of this simple family with modest means. Further troubles lay ahead when after just two years he developed resistance and had to undergo a Bone Marrow Transplant.

I was at his bedside when he was being prepared for this overwhelming procedure and in my mind can still vividly picture his beautiful family by his bedside. His wife and the two little girls - bemused and frightened but very, very calm; radiant with and radiating their love for him.

Sangeeta shares how when her father was diagnosed, she didn't even know what cancer meant. There was no access to Google or books that dealt with major diseases like this.

“The only books we had access to were comics and short stories. Being the elder child, I could sense the tension that filled in my small home. The air was filled with the moisture of tears and fear.”

The little girl decided in her own words, “to outsmart my parents and quench my curiosity by sneaking around files, listening to conversations, and glancing into the new books on cancer that suddenly filled the shelves of my house. The biography of Lance Armstrong was a book that was re-read many times. Gathering whatever I could

understand I learned that my father had cancer and the only conclusion I deduced was that death was near.”

A phrase that made the impact upon her was something she says that came up many times in much of what she read - The Pillar of the House”. The pillar of her house her father, “who now needed a temporary replacement when he was rushed to CMC Vellore for a bone marrow transplant.”

At the age of 11, Sangeeta accepted the role proudly and went on to handhold her eight year old sister and help their grandfather run the household while “my parents battled cancer 300 kilometres away.”

I cannot say it better than this young woman ... “Three months in the year 2006 changed many things in our home. My father was now a survivor, my mother turned into one of the strongest women who could endure anything, my sister an over-achiever at school in sports and academics, and when it came to me, although I lost the innocence of a child, I gained the wisdom of lessons life has to offer.

Cancer changed our lives for the better.”



Nuwan & his ‘Adored Daughters’

Interviewed by **Jyotiy Parmeshwaran**

Nuwan, 40 year old father of two “adored daughters” hails from the charming town of Kandy up in the mountains of Central Province, Sri Lanka. He himself was a young lad when diagnosed with CML; a vibrant 24-year-old, brimming with health and vitality; his days filled with sporting activities. He was a key member in his school and college martial arts team.

Today he credits his well being to his Oncologist Dr Kanti Perera who “seemed like an angel sent from above to guide me through the darkness; my very own unwavering guiding light”, and his loving partner, Dilhani who, despite facing opposition from all quarters, remained unwavering in her devotion to Nuwan and with her unyielding strength became his rock. He cannot stop wondering at how in the wake of his diagnosis, it was Dilhani who took on the roles of a diligent researcher, decoding the intricacies of CML to arrive at and understand the available treatment options.

It is important to share here Nuwan’s thoughts on how he handled the decision on how much their daughters needed to know about his condition and when they could become a part of the narrative.

He tells us how he gave this a lot of thought and how he was firm in his belief that until a suitable age a child should never have to bear the weight of the parents' medical challenges. Nuwan was very clear about shielding them till he knew they were ready to understand and see their father not as someone who was needy and dependent. “Shielding them from premature knowledge of this nature preserves their perception of their heroes, allowing them to grow unburdened by unnecessary worries.” Nuwan was able to present his diagnosis to his daughters not as a conclusion but as a “chapter in the book of my life”. It remains an integral part of his story, not a sentence of suffering.

Today, he feels victorious with their two adored daughters gracing their lives and a testament to the triumph of hope and resilience. “Gratitude flows not only to the medical marvels of Glivec and The Max Foundation but to the indomitable spirit that has carried us through as a family.”



Sanjeev & Ankit Jha

Interviewed by **Jyotiy Parmeshwaran**

Sanjeev Kumar Jha stands tall and proud no matter where and when he stands. If I run into him at the hospital where he is waiting to see his physician, he is not seated and waiting quietly; instead, he is running little errands for others or sharing his story or giving a little pep talk to someone. If it is at a patient support group meeting then he is bustling about looking after every little issue that needs to be taken care of; all the time welcoming the participants, making sure everyone is registered and the chai piping hot. If he is visiting our office then he is bursting with enthusiasm sharing his plans for the next Chai for Cancer Adda he is set to host.

It is no surprise that his children today are his spitting image. Ankit, Sanjeev's son, now a constant and willing volunteer at all meetings feels very proud that his parents are such incredible people; his father who is "fighting everyday with cancer, is always encouraging me to do the best in life. He teaches me to help other people who need assistance and support."

Ankit was eight years old and his sister ten when their father was diagnosed at the age of 32. The diagnosis and ensuing treatment costs was a big strain on this middle-class family. "As a parent, I wanted to give the best to my young growing children. But at times they were deprived of small things" says Sanjeev and tells us how he can never forget in the midst all other chores, his wife Usha would earn some much needed money herself by doing tailoring work from home.

Growing up under these circumstances, the children were many a time left to fend for themselves as their parents could not be with them all the time. Be it during their school examinations, holidays or even festivals, Sanjeev and Usha would have to leave them alone and travel to the big city for treatment. Their mother today proudly says how the children adapted so well all through those difficult days and situations

and have grown into responsible adults now. Sanjeev proudly adds. "They are well versed with the valleys and mountains of life."

Sanjeev and Usha have worked hard to educate and settle their children in life. They never miss an opportunity however, to acknowledge how the cancer experience has had such a positive effect on their children. It is this that has made them more courageous, more affectionate towards not just their parents but to others too. It has not been difficult to forget their past sorrows and they have learnt to move ahead in life with acceptance.

"They too want to help the cancer survivors, as much as possible from their side as they have grown seeing the this from their role model parents."



Kuldeep & Deepshikha

Interviewed by **Priyanka Kandalgaokar**

“Seeing my father, himself coping with cancer helping others and giving himself completely to their well being makes me feel so proud of him.”

Meet 29 year old Deepshikha who was just nine when her father Kuldeep Goel was diagnosed with CML. The middle child in the family, she is a chartered accountant by profession and currently working in Canada.

Kuldeep tells us how his main concern after his diagnosis was the fact that his young children would be unable to comprehend the seriousness of his condition and perhaps even the disease itself. He took the decision of bringing them to the Patient Support Group Meetings that he had begun attending regularly. It was consoling and reassuring to see how the children were getting the right information about CML from experienced doctors. Participating in the workshops and other activities made them feel an integral part of their father’s cancer experience. It mattered a lot to the worried father that this knowledge and understanding came to the young children at the right time ensuring they grew up secure in the knowledge that their father was part of a larger family with the support of many others who were in a similar position. It was this positive impact he wanted for his children- instead of the feelings of doubt, uncertainty and financial worry that consumed him and his wife in those early days. It had taken them a while to find the stability needed; a treating physician whom they could trust and access to the lifesaving treatment required.

Everyone calls me the carbon copy of my dad, says Deepshikha, though she is quick to say , no, not in the looks department where “he is way smarter than I am” but in his attitude and his beliefs . Deepshikha credits her own attitude towards her life to her father’s actions, his teachings - “because I saw the way he handled what life put in

his way. So I too faced whatever came my way and it made me strong and full of hope just like Dad. CML was a totally unexpected turn in his life and our life, but he paddled through that storm with full will power.”

Kuldeep is one of the most active and supportive of the Friends of Max City Chapter Leaders. His kind and helpful nature is inspiring and it is obvious this is one trait his proud and adoring daughter has imbibed from him. She calls it another life lesson. “I would say he led our life by example, an example of him being strong, helpful and never giving up. We have seen the lows of his health but today we feel blessed for what we have. I am proud be a caregiver to him.”



Omprakash & Arnav

Interviewed by **Sudha Samineni**

“Mealtimes - that time of day when everyone gathers together at the table; to share happiness or be in a carefree mood after a stressful day. It is quite an essential time for the child in the family too, because he gets to enjoy the special interaction with the family members and relish the food too. Mealtimes were never the same after the diagnosis.”

Perhaps the most insightful, heartbreaking and harsh truth; expressed and remembered with such innocence by a young man whose life was impacted so irrevocably when he was a little boy.

Arnav, this bubbly little boy who used to be the life and soul of every Patient Group Meeting in Bhubaneswar was initially completely unaware of what the daylong event he would accompany his parents to was. To him it was a day of fun and games, lots of food, some music or art or drama and lots and lots of people all coming together like a family. For a six-year-old child the word cancer meant nothing; least of all a life threatening event that might separate a loved parent from him. In his words.

“Attending Friends of Max (FOM) meeting with family would be like a fun Sunday outing without knowing the motive of these support meetings” he says.

But at some point in time it did register in his mind; how his father’s diagnosis changed the atmosphere in the house, changed the mood of fun family times.

Awareness of what was in their midst and a gradual knowledge about what it meant came about in his early adolescence years bringing with it great stress. “The more I tried to understand it, the more I used to worry about my father,” says Arnav today. “Attending patient support meetings with the Friends of Max used to energise my brother Aditya and I and we were now a team getting through this experience together” Arnav also feels it was being present and participating in these meetings that played a significant role in his brother’s life. Aditya chose to become a medical oncologist because “these meetings used to infuse him with the satisfaction of helping the people in one of the best ways possible.”

A few months ago I met the whole family for lunch when OP and Kavita were on a visit to meet their sons who both now work and live in Mumbai I could not take my eyes off the proud look on the faces of the parents as they watched their sons.



Bishnu & Pratiksha

Interviewed by **Sweta Agrawal**

Pratiksha Boudel, Staff Nurse working in the Hemato-Onco department at Patan Hospital in Kathmandu was three years old when her father Bishnu was diagnosed with CML. Her newborn brother was a week old. In all these 22 years says Pratiksha, she has never seen her father lose hope or faith and give up. Instead, she has seen how he has gathered every bit of courage and worked towards not just managing his own cancer but through his actions and untiring work motivate and inspire hundreds of other patients.

None of it was easy, says Pratiksha. When she looks back at these 22 years what she vividly remembers is seeing her father go through exhausting situations and gathering strength to accept and deal with various challenges that came his way. What was alarming was the manner in which his disease progressed necessitating switching from one treatment modality to another and dealing with its resulting complications. As little children in Junior School both Pratiksha and her brother struggled hard coping with his absences. Seeking the appropriate treatment meant their father had to stay away from home for long periods of time.

Bishnu Dai (Dai is elder brother in Nepali) looking back upon that time 22 years ago, remembers his confusion, the fear and the questions to which he had no answers then. How long before the cancer claimed him and what would happen to his young family? How will his wife take care of his mother and children alone? What about their upbringing and education?

Being able to access treatment through The Max Foundation Access Program made a big difference he says and gave him tremendous confidence and courage. The desire to give back to community took root. During his follow up visits to the hospital, he saw other patients who too, just like him had no answers to the questions plaguing their minds. Gradually he started advocating for them helping them understand their diagnosis and its impact. In that service he saw his own life, which was hurtling towards darkness, experience light and hope.

Pratiksha was inspired by her father and motivated to find a future in health care. She has hopes of continuing her studies in the US, even as she discharges her nursing duty in her country today. This father and daughter duo truly show us how cancer has given new meaning and direction to their lives.



Sailaja and Aradhana

Interviewed by **Sudha Samineni**

Sailaja was a young mother of two, living as she herself puts it, an idyllic life.

And then a cancer diagnosis and the reaction: “this couldn’t be happening to me; surely there must be some mistake”. Unfortunately, there was no mistake and she realized that she had indeed been ignoring a few, what she now recognised, as warning signals – fatigue, weakness, loss of weight ...

“Cancer was supposed to happen to others, how come I got it?” That inner voice screamed, soundlessly. The young mother was devastated. “If I was no more, who would take care of my children...?” Sailaja was a mess. The life she had taken for granted, the life she thought lay ahead of her was a lie and now perhaps she would never see her kids grow into adults.

Anuradha her bright young daughter was perhaps seven years old then and has some vague, blurred memories of her mother falling sick all the time. Her parents would be away some days for short periods of time and return home with no smiles on their faces. It seemed they were enveloped in a pall of gloom all the time. When they did tell her eventually, Anuradha was still young enough and could think of nothing else except that her mother would probably die and leave her, her brother and her father all alone. She herself now says that she wasn’t old enough to understand what the disease her mother had was exactly. In her confused and frightened state she related it to some film she had watched in which the hero dies of a heart problem. As is wont with children however, after a few nights of crying, it was all pushed into the recesses of her mind and the little girl’s life continued.

Sailaja remembers those traumatic times, especially the first six months; when her oncologist had very few answers to her queries and neither did she have anyone to share her fears or clarify doubts regarding the medication and its side

effects. After all she had been told she had to be on lifelong treatment.

“It was The Max Foundation’s CML group created by Viji amma that came to my rescue! It was my source of all information. Being part of Friends of Max meant we could share our experiences, talk about the management of side effects and various CML monitoring tests. This really saved my sanity and my life and gave me Hope.”

Then a few years later, while on a visit to her grandparents’ home in Delhi, Anuradha accompanied her mother to her first Friends of Max meeting. In the book of patient testimonials that was brought out at this All India gathering, she read her mother’s story and tells us how it was only then that she was consciously able to process all that had happened. Going through stories of other patients it became evident to her how so many other families too had all gone through a similar experience.

Then after perhaps 18 months or so came the Bangalore All India Meet where again Anuradha accompanied her mother. “I met and spoke to other patients and caregivers like myself. After meeting so many people I realized that my mother wasn’t alone in her battle.” Anuradha says she realised now that there were many other people going through the same experience, not just people of her mother’s age but also youngsters in their teens. “I met friends of my mother’s – some people had just gotten married, some had kids in college, others were old enough to have grandchildren. They all seemed to get on well with their lives with their dreams and hopes and families. The greatest courage I got was after seeing the wonderful community that was The Max Foundation and Friends of Max family.”

At the Hyderabad meeting I remember Anuradha proudly going on the stage and singing a song, accompanying herself on the guitar. To me she represented the courage she ascribes to her mother.

In her own words: “My mother never once complained, never cried, never felt sorry for herself. She ran through a burning field, swam through an ocean and flew over the mountains. Nothing ever stopped her. I can only ever hope to be half as brave as her.”

We are Invincible says Anuradha.

“Despite all these years of pain, all cancer patients have managed to create an utopia for themselves within the chaos. If all of these years haven’t done any damage to us, we can safely assume we are invincible. We are brave. We are young. We are infinite.”



Hirji Narayan Dama and Vijay Bhiku Shelar

Interviewed by **Anshika Tandon and Urvashi Negi**

The gentle and mild mannered Hirji Dama, now 52, was only 29 years old when diagnosed and didn't have the courage to tell anyone about this great calamity that had befallen him. His wife was eight months pregnant with their third child and the initial days of treatment were difficult. He tells us how it took him nine long years to share the news of his with the family.

His elder son was only five years old, the younger was two and his beloved daughter was born one month after his diagnosis. Hirji worked in a grocery store and somehow managed all the household expenses.

With his modest earnings Hirji and his wife educated their children as best as possible. The Max Foundation access program was the boon they never hoped for. Both his sons are now married and settled with jobs in the service sector. With quiet pride he tells us how their parents' struggles have made them humble and resilient. When Hirji talks of his daughter his eyes light up altogether with another glow.

"My daughter is my strength. Her birth forced to me look at life with a different perspective and she came to me as a blessing. Her name is Rashmi, and she recently cleared her Chartered Accountant examinations," says the proud father.

It is the Patient Support Group Meetings that he never misses Hirji says, that have helped him in coming to terms with his disease and he sees a change in his attitude. "We as a family attend these meetings, including the recent one at Tata Memorial Hospital, Mumbai in June where I was accompanied by my daughter as well as my daughter in law."

Having shared his experience with his family, especially his children is what helped him to stop fearing cancer he says and would suggest to all newly diagnosed patients to do the same. Also, he says, "adhere to treatment protocols given by your physician. This is the only rule to living with the disease."

48-year-old Vijay Shelar was diagnosed over 23 years ago and came into the program a year later. He spoke to us about his diagnosis, relationships, and the principles he wishes to inculcate in his young children. A parent being diagnosed with cancer makes the already difficult process of dealing with a cancer diagnosis even more challenging. It's not simple to carry the responsibility of explaining the same to their children without causing them emotional distress. Like Hirji Dama, Vijay is also of the opinion that if you have chosen to speak up to your children about your diagnosis, it is vital that you communicate with them openly and honestly and give them time for processing the information.

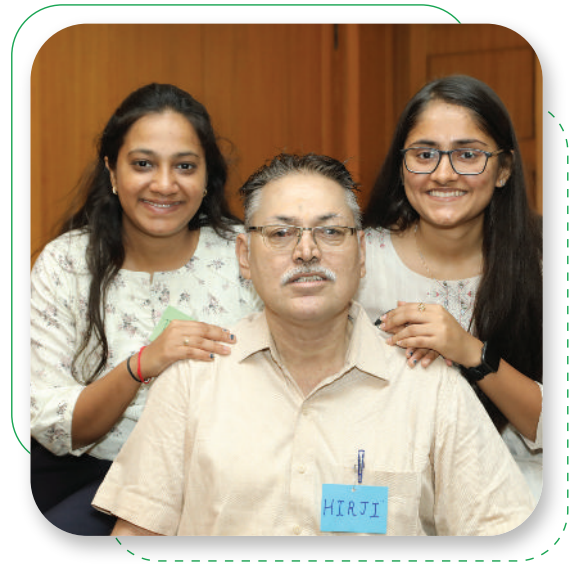
Vijay married in February 2005 and he and his wife now have three children between the ages of 15 and seven. Even though the knowledge of his diagnosis had initially terrified his wife, she was ready to stand by his side willing to share his journey.

Vijay decided to bring her to the Friends of Max meetings and through these patient support group sessions he tells us that she gained the fortitude to deal with the situation. They both learnt and understood that he would be well if he continued to be compliant with the therapy.

Most importantly, Vijay says that through these meetings she learnt how this disease does not spread through touch and that it was possible they could even have a family of their own.

Their first born, Saloni is now in 9th Grade and Vijay says she is now old enough to be aware of his condition. Ever since she was told of his CML she has only shown strength and support. “She continues to be one of my biggest supporters because she recognizes that I have not let this diagnosis hinder me in any way.”

Vijay tells us that his message to his family is that no matter how difficult life becomes, we must continue with the struggle valiantly. “Come together, think together, and work together is something I wholeheartedly believe in.”



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Together we share & learn

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