

Coping with cancer and COVID

Here are some inspiring stories from the field that showcase how important food is for kids and families fighting childhood cancer.

Oliviya Sumi – 5 years, Leukaemia, Guwahati

During the lockdown Cuddles ensured uninterrupted nutrition for five year old Oliviya battling Leukaemia who was forced to move 200 kilometres from Dimapur, Nagaland to Guwahati, Assam for her monthly supply of nutrition and cancer treatment.



More than two years ago, 5-year old Oliviya Sumi was diagnosed with Leukaemia. Before the lockdown, Oliviya and her parents would regularly visit Guwahati's Dr. Bhubaneswar Borooh Cancer Institute (BBCI) hospital for her check-ups and treatment. Her mother Shikhatoli recalls, "Earlier we took the rations supplied by Cuddles for granted. But when the lockdown happened, I feared for Oliviya and how would I feed her?". Shikhatoli took the courageous call to leave behind her husband and son in Dimpaur and boarded the train for Guwahati, just to secure Oliviya's treatment and the monthly supply of nutritious rations.

Just two months ago, Oliviya's father quit his army job and returned to his family in Dimapur to support his wife and the rest of the family through Oliviya's illness. Covid wrecked the family's plans and the mother and daughter are now physically and financially distanced from the rest of the family. They have now rented a room in Guwahati which is an additional burden of Rs.6000 every month.

With the lockdown paralysing supply chains and hospitals out of bounds for most non-COVID patients, Oliviya's mother was also worried about securing food supplies that the

family had grown so dependent on. Shikhatoli reached out to Momi, Oliviya's nutritionist from Cuddles who despite the lockdown arranged for the rations to be delivered directly to Oliviya. With rations reaching their doorstep, Oliviya is eating healthy and staying nourished. Something she could have been deprived of during COVID, if she was stranded in Nagaland.

Tonoto Zhimomi, 11 years, 4th Stage Brain Tumour, Guwahati

Need for nutritious food, treatment and the threat of eviction forced 11-year old Tonoto battling cancer to leave his family behind and move to Guwahati with his mum.



11-year old Tonoto Zhimomi was diagnosed with Medulloblastoma, a fourth stage Brain Tumour. His mother, Vilika Zhimomi, travelled from Dimapur, Nagaland to Guwahati, Assam leaving behind two other children and Tonoto's father who had to stay behind to manage the family-run meat shop.

The pandemic forced him to shut-shop. And their landlord in Dimapur threatened eviction if Tonoto continued visiting the hospital for check-ups, for the fear that he or Vilika may bring back COVID.

Tonoto's treatment and nutrition could not be compromised so the family was torn apart by COVID. Tonoto and Vilika shifted to a lodge near Guwahati's BBCI hospital. But COVID added to Tonoto's existing anxieties of fighting cancer. What they needed was one less thing to worry about and Momi, the Nutritionist from Cuddles, assured Tonoto that despite

the pandemic he will not go hungry and promised him a steady supply of rations and supplements.

Ayush Yadav, 5 years, Wilms Tumour, Varanasi

A grandfather's 200-kilometre cycle journey with his 5-year old grandson to Varanasi for treatment of his tumour and for ration.

As soon as Ajay Kumar Yadav heard of the first Janta Curfew announced by the government, he set off on a 200-kilometre cycle journey from Ghazipur to Varanasi. His 5-year old grandson, Ayush, who suffers from Wilms' Tumor, rode pillion the entire distance and it took them more than 48 hours to get to the Homi Bhabha Cancer Hospital.

The grandpa-grandson duo decided to undertake the harsh road-trip to ensure that if the lockdown was an indefinite one, they will be close to the source of two things they need the most. Treatment for Ayush at the hospital and the food he needs to keep him nourished.

Ayush was diagnosed with a common type of kidney cancer called Wilms' Tumour. Born into a family of migrants from Gazipur in Uttar Pradesh, Ayush's father is a daily wage labourer. Ayush started his treatment and nutrition counselling in December and gets the monthly supply of rations from Cuddles. The lockdown forced his grandfather to move to Varanasi to ensure that Ayush does not miss out on his diet that has been tailored to meet his nutritional requirements.

Aisha Khatun, 9 years, Bone Tumour, Vellore

After the collapse of his business due to COVID, the father of 9-year old, Aisha Khatun, reaches out to Cuddles for ration.

As Sister Nalini, a Nurse at the Paediatric Oncology department of CMC Vellore, was going about her routine rounds at the ward she was approached by 38-year old Mohommad Firoz Ahmad. His 9-year old daughter Aisha Kahtun is being treated for Bone Tumour at the hospital. A few days ago Mohommad ran a small business. Which collapsed soon after the lockdown started.

An educated man, Mohommad, told Sister Nalini that so far he had been able to support his family with his business and was able to take care of Aisha's treatment and nutrition needs. But COVID forced a closure of his business. With no help from his extended family, a distraught Mohommad reached the hospital to ask for a bundle of rations for Aisha. He said he never thought he would have to depend on free ration supplies to feed Aisha and her siblings.

Sister Nalini consoled Mohommad and asked Cuddles social worker, Deva Priyanka, to give him supplies for a month. When he saw the bundle he broke down sobbing while holding on to it.

But getting Aisha nutritious meals is not the end of Mohommad's worries. His wife Sunehri is two weeks away from delivering their third child. Now the nurses and staff at CMC Vellore are fundraising to help Mohommad meet the expenses of the delivery and care for the baby. Well we are grateful yes, but this is hard. And maybe this is just the way things are going to be for some time. This is a long haul for families of children like Aisha.

Vibha Singh, 14 years, Blood Cancer, Lucknow

Severely malnourished and diagnosed with Blood Cancer, 12-year old Vibha underwent nutrition therapy at Cuddles. Two years later she gained 14 kilos and is now under maintenance.

Nearly two years ago a 12-year old Vibha Singh started getting intermittent spells of fever. Initially she was at the mercy of a village who failed to treat her. Even showing her to doctors at nearby private clinics did not lead to an accurate diagnosis and she was finally referred to the SGPGI hospital in Lucknow.

Vibha's parents were informed about her diagnosis of blood cancer. They thought cancer is an infectious disease and they separated Vibha from her brothers and sent them away to live with relatives. At the hospital Cuddles nutritionist, Swamitha, prescribed an intense 5-month nutritional rehabilitation programme for Vibha to boost her immunity.

The diet helped Vibha who was living with her mother in a single room near the hospital and she started to gain weight. Both she and her mother depended entirely on the monthly ration bundle for their nutritional intake. Vibha, still a kid at heart, always looked forward to her chocolate flavoured drink which was part of the supplements prescribed to her.

All this while her father Kaptan Singh a construction labourer was away from his daughter working in the villages to support his family and the education of his two sons.

Vibha is now a teenager and with her health improving and now under maintenance. Her recovery is a success story of how cancer treatment coupled with nutrition therapy is essential for child cancer patients whose families don't have the means to take care of the nutritional needs of their children.

Noorena Khanday, 13 years, Acute Lymphocytic Leukaemia (ALL), Srinagar

In locked down Srinagar the mother of a child cancer patient shares her monthly ration supply with another child battling cancer.

In April, days after Srinagar was placed under lockdown like the rest of the country, Shabbir Khanday was wandering in the corridors of the SKIIMS hospital of Srinagar desperately searching for Cuddles' nutritionists. His 13-year old daughter, Noorena Khanday, who gets treated for Leukaemia at the hospital also relies on it for monthly ration and nutrition therapy.

In the chaos of the lockdown, Shabbir lost his phone, and along with that the numbers of nutritionists Khushnuma and Rakhia who assessed Noorena's nutrition and would give her the bundle of monthly ration. Shabbir, a construction worker from Bundgam, has been without work since August last year. He had to give up working to be in Srinagar for Noorena's treatment.

Shammema Darzi, the mother of another patient, Rutba, who also suffers from Leukaemia, found Shabbir crying in the hospital parking lot. She heard him out, and without hesitation, parted with half of her daughter Rutba's rations and gave them to Shabbir for Noorena. Cuddles nutritionists Khushnuma and Rakhia heard about this kind gesture and ensured that the first supplies for the month of May and last month's ration which Noorena's family missed out on reached them.

The vendor, Mohommad Yaseen, who supplies ration bundles also offered free rations to Shabbir in the future if he was unable to collect them from the Cuddles team in the hospital.

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www.cuddlesfoundation.org