

## **A CAMPER'S DIARY**

*Ms. B. Menon*

E-82, Ansari Nagar, New Delhi-110029

The public is aware of the word diabetes, but few could identify the social and psychological conflicts, the pains and pangs of young minds suffering from childhood diabetes mellitus. The term "living crucifixion" was used by a young girl while narrating her experiences of being a diabetic patient and it shows the depth of the pains she is passing through. And she is one among the thousands and thousands of children suffering from juvenile diabetes mellitus in India. All India Institute of Medical Sciences, New Delhi and Postgraduate Institute of Medical Education and Research, Chandigarh, under the auspices of Research Society for the Study of Diabetes in India and Diabetes Foundation—India, organised a camp in May 1988, to educate and train young diabetics to control the disease well and not let this illness be an 'inhibiting factor,' throughout their life.

A group under the guidance of eminent diabetologists, pediatricians, dietician—nutritionists, nurses, health educators, technicians, other volunteers and parents and the most important participants—30 young diabetic children and youth (also 15 youngsters without diabetes), embarked on this memorable venture on May 24th 1988, with a hope in the heart and a twinkle in the eye.

The long journey from Delhi or Chandigarh to Summer Hills, Simla during the peak of summer was 'tiring' for the children, but as one young patient remarked 'It was worth experiencing'. The children in travel were initiated on, as Prof. MMS Ahuja put it, "self confidence and self management" from the very word go.

The day at the camp begins with the first rays of the sun. Day schedules are formulated with exercises, health check ups, blood sugar testing, meals, educational and recreational activities. After the morning chores are completed, they are off to a jogging trip downhill through the meandering alleys in the mountain trail. There is a glass of a fruit drink or milk for those who specially need it.

The first meal is breakfast. The children after their blood checkup and insulin injections rush towards the 'laid—table' where a judicious mixture of nutritious food is served. The children are asked to eat on their own but to keep a check on what they eat. They have to fill in their diet cards, what

they consume and calculate the caloric, protein and fat content. There is a counsellor at each table to guide them on individual food intake and how to calculate with simple charts and adjust their food intake.

After breakfast the children along with the supervising staff assemble in the main hall and a 'thought of the day' is presented by one of the campers. The first day starts with "Truth". As Prof. Ahuja explains the importance of being "truthful to oneself" while managing diabetes, the campers come out with their own experience and experiments with truth. The very first discussion thus initiated is near the camping room at Raj Kumari Amrit Kaur Bhawan, where Mahatma Gandhi had spent few of his wonderful days every year prior to Indian independence. Many more themes emerge which form the guiding spirit during the rest of their stay (will, health, discipline).

There is a short period of relaxation and a midday snack is ready for the children. Then the education classes begin. There is one set of discussion sessions for the campers and another for the professional staff. What is diabetes? A disorder characterised by a failure of pancreas to secrete an adequate supply of insulin. Why are children different from adults with diabetes? Because most if not all children need insulin to correct the disorder and that too lifelong ("insulin for survival"). Thus begins the teaching sessions. Experiences are recounted, problems are discussed and unanswered questions are put forward for all to give their own suggestions. The main symptoms of diabetes are excessive urine output, excessive thirst and increased food intake associated with high blood sugar and sugar in urine. The control of diabetes through proper schedule consisting of diet, physical activity, insulin administration, regular urine/blood sugar monitoring and general hygienic care are demonstrated. There is a discussion on diet and the need for basic essentials such as fats, carbohydrates, proteins, vitamins and minerals are explained. Diet plans are discussed and individual diet charts analysed with respect to their glucose control and insulin needs. Superstitions and beliefs about diet, insulin, exercise, studies, job prospects and future life are discussed. A consensus emerges that diabetes is not just abstinence from sugar and invalidity is not synonymous with it. It is upto you to lead a happy life of your own, provided you can organise your life a little better.

It is not all classes alone during the day. Except for the organised sessions, the children are free to do what they feel like with prior intimation to their counsellors. May be a small trek down to the nearby Baleaganj and breathing the pine scented air. Or a game of table tennis or badminton in the nearby open ground. Our dear Manish will have nothing else but a game of

football in the evening. But all are ready with their candies or glucose packets in case they need them.

And all is not well in camp as in any household. Young Prithpal has injured himself while he runs down to collect the football. Harmeet is feeling giddy and Anjali is feeling tense and tremulous. But there is no sense of panic in the camp. Shobha, the nurse/health educator is busy preparing the lime—glucose drink and Krishnan is ready with the glucometer for the instant blood glucose reading. Drs. Manisha, Anil and Ram are there in the cabin to oversee that nothing is amiss. And the first aid team with Sister Kumar in charge of the infirmary is attending all minor ailments. Drs. Sood and Bichha are on rounds to see that every child had his insulin and food.

There are a lot of things to learn from all these. It is important to keep oneself healthy, free from all infections to lead a normal ('near normal') life. That means looking after oneself—attending to minor ailments, cuts and bruises early enough to prevent complications later. It is necessary that you should be able to recognise "hypo" (hypoglycemia=low blood sugar) attacks. It does not manifest the same way in all. Unlike Harmeet and Anjali, Navin has a sensation of 'chakkar' (vertigo) when he is in hypo. Shobha goes into laughing spells during such attacks. It isn't enough to take insulin injections alone. The crux lies in monitoring your urine/blood glucose. And Dr. Menon tells them in one of the sessions that better your control, the lesser the chances your brain, kidney and eyes will be affected.

There are films to watch and the omnipresent telly and video. There are films to enjoy in the evening—'Qayamat se qayamat tak', and there are videos which show how to prevent the 'Qayamats' of diabetes. In the "evening get together" before/after supper, there are voluntary and spontaneous presentations: poetry, recitation, songs, ghazals, dances etc., One afternoon children crowd the main hall busy with their on the spot painting competition. Hats off to Drs. Kavitha, Rupinder and friends for arranging all the fun; also prizes for the kids. There are non-diabetic children too, family members of the diabetic children and children of the professional staff. All are treated at par. Amusement spreads to the diabetes education classes too, where Shobha is ready with her colored posters and cartoons on "Mannu" the baby elephant who developed diabetes and is trying to learn how to control it through the jumbled maze of 'hypos' and 'hyper'; and of course the story ends with a learned and disciplined "Mannu" who lived happily ever thereafter.

All activity is not confined to the beautiful old palace: Rajkumari Amrit Kaur Bhawan and its sprawling periphery. There is a shopping trip to the Mall. There is a day for picnic to Naldhera (golf course). There is cricket, frisbee, throwball and other games around. While the balls fly and enthusiasm mount, the 'food team' (under Ms. Alka and Uma) are busy arranging 'purees', salad and fruits for the hungry and exhausted. There are pony rides and treasure hunts. While Lara is singing with her guitar, Anjali is mentally composing a new poem. The cumulative laughter of the children echoes the mountain side.

As the day wears out and the tired children are finally sound asleep at the Camp Man Mohan (Camp MM), the night duty doctors are on prowl to detect any with asymptomatic 'hypo' attacks. The day's activities are over and the final plans for the day ahead are being discussed inside the camp office. There is tension on the faces of Drs. Garg and Sri (camp administration). There is milk and bread to be bought for the breakfast and a special cake to be prepared for a party, as it is Dr. Karmarkar's (Dr. Do-die-do) birthday tomorrow. Finally when they sleep, it is time to get up for the next day's work.

Good days never last forever and it was with much reluctance the children (and the staff) had to pack for their return homeward journey. For most, this has been their first outing in a group away from the maddening crowd, and in a tension free atmosphere. Most important, this is the first time they are on their own, learning and living with diabetes.

As the bus scuttles back through the winding roads of Shimla and as the group leaves behind so many beautiful memories, some flashing shots crowd my mind. Of Manish, who is crying in the bed because he has lost his football, Amardeep who would not eat his breakfast because he was found to have high blood sugar in the morning. Mona having her first pony ride, Nagashree worried whether the morning outing trip will be cancelled because of her 'hypo' reaction. And Amit guzzling two bottles of Limca on the bus—for the first time in his life, since diabetes. The dancing children around the camp fire, the entire team in the camp-T shirts standing for group photographs, Prof. Ahuja surrounded by children in the morning assemblies—answering questions and queries of all sorts from the curious, inquisitive and tender minds.

Thus the Camp—I is over and with that many doubts and worries cleared. They know that they have a chronic disease to bear with all their life, but it is not difficult to control it with a little "self—care". It is no longer the "living crucifixion" they had feared. In fact, the first, question as they alight from the bus is "When is the next camp?"