

<u> Mishti - Guardian</u>

(a CDiC initiative to empower parents and families of children with type 1 diabetes)

Issue - II

Editorial Team

Dr P. Raghupathy

P Dinakaran

Dr Shuchy Chugh

Dr Bharathi.R

Anupama Rau Attawar

Advisory Team

Dr A K Das

Dr AK Jinghan

Dr Alok Kanungo

Dr Archana Sarda

Dr Banshi Saboo

Dr Bipin K Sethi

Dr KM Prasanna Kumar

Dr Manoj Chadha

Dr Nalini Shah

Dr Nikhil Tandon

Dr P K Jabbar

Dr P. V. Rao

Dr Rajesh Joshi

Dr Rishi Shukla

Dr Sanjay Kalra

Dr SS Srikanta

Dr Subhankar Chowdhury

Dr Sunil M Jain

Dr Surendra Kumar

Dr Vaman Khadilkar

Dr Vijay Viswanathan

It gives us immense pleasure to bring out the second issue of Mishti Guardian newsletter, a medium to connect parents of children with type 1 diabetes with diabetes educators and doctors. At the outset, we would like to thank everyone for your appreciation of our first issue. This newsletter aims to share practical real life experiences and bring into discussion appropriate preventive measures or possible actions to help children with type1 diabetes grow into healthy, responsible and independent adults.

Sometimes as a parent or an elder, we tend to be overprotective of our children especially, when they have a disorder to manage. Do not overburden yourself with work and thoughts about type 1 diabetes. Respect your instinct as a parent. Do not fill yourself with guilt if something at some point goes wrong. Just keep on learning about diabetes from the treating doctor and you will do the best. Michael Jordan, the famous basketball player once said "Obstacles don't have to stop you. If you run into a wall, don't turn around and give up. Figure out how to climb it, go through it, or work around it." This can be an inspiration for all of us.

This second issue has an interesting article from Prof Raghupathy about how to manage diabetes while enjoying holidays for children with type 1 diabetes. Dr Rishi Shukla writes on "Marriage and People with type 1 diabetes". We also have a very interesting article by Dr Sanjay Kalra about the role of family in implementing diabetes therapy. A brief note dispelling myths about eating fruit and also the recipe of mixed fruit smoothie — a yummy summer delight is also part of this issue. We bring out this issue, with an aim to facilitate the appropriate attention for the child with diabetes in various situations of life by sharing knowledge from medical experts who have been working hard for the well-being of these children for a long time.

This is an initial effort. We are sure this will meet its objective by being a useful ready reference material for all caregivers of children with type 1 diabetes. We will like to receive your continuous feedback and suggestions to improve and strengthen Mishti Guardian.

With best wishes.

Editorial Team











Tips for enjoyable summer holidays - Dr P. Raghupathy

Summer vacations are most enjoyable part of the life of any child. No school, no studies, lot of games, visit to grandparents, new places, waking up late in morning and endless other excitement. Unfortunately, these holidays are from school... and a child with type 1 diabetes cannot take holiday from diabetes management. Changes in routine, although enjoyable, can make diabetes more difficult to manage. Let's understand how summer holidays affect a child's lifeand how diabetes should be managed.

1. Situation: Change in Routine

With no school, children tend to get up late, play more and have food at different times. Diabetes does not mean that child should have the same routine as that of school days. It means that the child can very well have a different routine. Only this routine needs to be followed throughout the holidays. Please see below for a suggested time table for holidays.

Action Needed

- It is better that a new routine is established in the first 2-3 days of the vacation and blood glucose levels are monitored frequently as suggested by your doctor.
- Discuss the changes and results with the doctor and diabetes educator, act accordingly and enjoy.

2. Situation: Exercise during holidays

Exercise routine often gets disturbed, because of travelling, sleeping, being with friends, going to visit relatives. Also playing, roaming, shopping, sightseeing and other physical activity may lower glucose levels. It is certainly not advisable to spend holidays watching TV. Physical activity is healthy.

Action Needed

- Try to follow your exercise schedule even during your holidays
- Take overall activities into consideration when deciding diet and insulin dose and always be ready to treat hypoglycaemia - carry

Insulin in use need not be refrigerated, but insulin should not be stored in very hot or very cold temperatures as it may lose its strength. Insulin should always be kept away from sunlight (away from window seat in a car, bus /rail) in a cool dry place (not in glove compartment of car or in parked car) It is better to keep insulin in a cool pouch to maintain temperature.

Normal Time Table

Time	Activity
05:30 AM	Wake up and brush teeth
06:00 AM	Have Milk and do exercise, bath
06:30 AM	Get ready for school
07:00 AM	Take insulin
07:30 AM	Breakfast and leave for school
10:00 AM	Snack break in school
12:30 PM	Lunch break in school
03:00 PM	Return home and snack, play
07:00 PM	Take insulin
07:30 PM	Dinner
09:30 PM	Night snack & sleep

some form of sugar or carbohydrate always with you to treat low blood glucose.

3. Situation: Food intake during holidays

Summer is the season of mangoes, melons and ice-cream. Visit to grandparents or relatives place can also disturb one's regular meal plan.

Action Needed

- Learn about food exchange and you can have one slice of mango or 1 cup melon cubes in exchange of your other fruits. Remember, nothing is prohibited, but moderation is the key to indulge, enjoy and yet have good blood glucose control.
- Inform in advance about your diet requirements while visiting your relatives. Take your insulin shot only after the prepared food is ready in front of you. Otherwise, a delay in getting the meal following the insulin injection may lead to low blood glucose.

4. Situation: Travelling to new places

Whether it is a long trip or a short one, diabetes and its management needs to travel along with you as travelling can affect blood glucose levels in many ways.

Action Needed

Always carry your diabetes prescription and supplies with you. Carry your insulin, glucometer, blood glucose strips, syringes and hypo treatment kit in your handbag or in a place easily accessible whether you're travelling by airplane, train or an automobile.

Holiday Time Table

Time	Activity
07:00 AM	Wake up and brush teeth
07:30 AM	Have milk and do exercise, bath
08:00 AM	Take insulin
08:30 AM	Breakfast
11:00 AM	Snack break
11:30 AM	Dance class / play
01:00 PM	Lunch
04:00 PM	Snack, visit friend's home and play
08:00 PM	Take insulin
08:30 PM	Dinner
09:30 PM	Night snack & sleep



Life story of Kiran

(Age - 5 years, living with type 1 diabetes for 4 years) *

Kiran is under care of Dr. P V Rao. This story is narrated by her parents to Dr. Indrasen Reddy from DRS, CDiC centre, Hyderabad.

Please note that name and few specifications of the child are changed to keep the identity of child confidential.

Brief Background:

Kiran is a single child of her parents. She was a precious child since she was born after four years after blessing of a spiritual guru. Her father works in a private company. Her mother was working as a teacher in a private school before her birth.

When and how the family came to know about Kiran's type 1 diabetes

Kiran was diagnosed to have type 1 diabetes four years ago. This happened two weeks after her 1st birthday. It was summer time and her mother observed that she had started drinking water like adults. At that time, she had started looking very pale and weak. Her parents thought that it may be due to some evil eye. Her grandmother, who herself had type 2 diabetes observed that Kiran was passing urine very frequently and it was sticky too. She asked Kiran's parents to take her to the doctor. Her parents took her to a nearby hospital. At that time, she was very irritable and had difficulty in breathing also. She was immediately admitted in the hospital. Her random blood sugar levels were 593 mg/dL at that time. Doctor said that if they had further delayed bringing their child to hospital, it could have been difficult to save her. She was diagnosed to have diabetic ketoacidosis.

Issues and beliefs

It was a shock for the whole family as no one knew that diabetes can happen in children also. No one in the family knew about type 1 diabetes and importance of insulin. Her both paternal grandparents and maternal grandmother had type 2 diabetes and they were reluctant to give injections to such a small child. They advised her parents to take Ayurveda and Homeopathic treatment. Her father had observed how insulin had saved life of his child but was confused. Her parents

decided to give every kind of treatment along with insulin. It was a huge financial burden for them. Their resources were depleting and they thought about taking loan from money lenders to save their only child.

Journey of living and learning to manage diabetes

After her second birthday, through a family friend they came to know about Diabetomics CDiC center in Hyderabad. They visited Diabetomics and got her enrolled in the CDiC Program. She started getting free medical check-up, insulin, glucometer, strips and regular diabetes education. Repeated counselling was given to her parents by doctors, staff nurses and diabetes educators. Now, Kiran and her family members have learned many things on management of diabetes, such as hypo-glycaemia (low blood sugar), hyperglycaemia (high blood sugar) and also that insulin is Kiran's best friend. They also know that as today diabetes is not curable disorder and can be managed only by insulin and right diet.

Environmental Factors influencing child's life

School - She has recently joined kindergarten. Her school principal was counselled by one of the educators at CDiC centre. Her school is very cooperative with the family.

Medical center - Her parents listens to all the instructions given by doctors, educators and dieticians. Her mother tries her best to follow them and now Kiran is having good control over diabetes.

CDIC - From the time she got enrolled in CDiC, she has been regular in the follow up visits. Her parents feel that this holistic program is blessing in disguise and treatment is great help for them and otherwise they would have been in a mess.

Camps - Her parents love to come to camp. Her mother had made many friends with parents of other children with type 1 diabetes in the camp. She is motivated by seeing many small children present in the camp. She is very close to a 17 years old girl who was diagnosed at age of three. She hopes that one day her daughter will grow and become a doctor.



Can children with diabetes eat fruit?

Healthy eating is important for all children, including those with type 1 diabetes. Children and adolescents need sufficient nutritious foods to grow and develop normally. Children with type 1 diabetes have the same nutritional requirements as other children. Fruit is a food group, which all children are encouraged to have on a daily basis. Along with vegetables, they are rich in essential nutrients, vitamins, minerals, antioxidants and fibre. Fruits also have relatively high sugar content and it is common for people with diabetes to have questions as to which fruits are best for them and how much they should consume.

Diabetes Management – The final aim for any diabetes management is to keep blood sugar levels near normal range at any point of time. It is advised to consume at least 5 portions of vegetables and fruit in a day. Fruit contains carbohydrate so you need to count it as part of your meal plan. All carbohydrate-containing foods, weather it is roti, fruit, or milk can affect blood sugar levels. It is the amount of carbohydrate you eat (not the type) that has the biggest influence on blood sugar levels. Keeping this facts in mind, children with diabetes can eat all kind of foods (including fruit) with some planning. The American Diabetes Associations recommends fruit as a good option for a snack and can be taken instead of a dessert. Having a serving of fresh fruit for dessert is a great way to satisfy your sweet tooth and get the extra nutrition you're looking for. When deciding which fruit to have and how much, having access to carbohydrate values and a blood glucose meter offer the best guides. Too much of any carbohydrate at a given meal or snack will probably raise your blood sugar higher than you would like.

Diabetes, fruits and myths

1. Myth - It is a common myth that if you have diabetes you shouldn't eat certain foods because they are "too sweet" like mango and banana.

Fact - Some fruits do contain more sugar than others, but that doesn't mean you shouldn't eat them if you have diabetes. By keeping in mind the quantity of fruit one can enjoy various fruits. Eg. The following fruit servings contain about 15 grams of carbohydrates: 1 Small Apple =1/2 medium banana = 1/2 mango= 3 Dates= 1 & 1/4 cup watermelon=1/2 chikoo= 1 Guava =15 Grapes=1 Orange= ½ pomegranate=1 kiwi =2 Figs = 2-3 slice of papaya= 3 Plums= 2 slice pineapple. Eating whole fruit is more beneficial as it has more fibre. A person with diabetes can eat any fruit, but the quantity should be measured.

2. Myth - You should have same fruit every day.

Fact - You can have same servings of any fruit at a given time. Eg. If at 11.00 AM daily you take 1 apple, you can have 1small orange or 1/2 small Mango also. Different fruits are rich in different essential nutrient For example Mango contains a healthy amount of vitamin A and Orange contains Vitamin C. Changing fruits is a good practise but the key is to keep an eye on portion sizes and stay away from fruits canned in syrups or other types of added sugar.

3. Myth - Fruit and fruit juice are one and the same thing.

Fact - No, fruit juices usually have less or no fibre. Fibre helps digestion and may help stabilize blood sugar levels as it causes release of glucose into the cells more slowly.



 $= \frac{1}{2}$



= 3



= 1 ½ slice





Some points to remember:

- 1. The best choices of fruit are any that are fresh with edible skin and seeds in moderate quantity
- 2. Dried fruit is higher in carbohydrate than undried fruit. Be cautious when choosing dried fruits and fruit juices. They can be worked into a diabetes meal plan, but as both options are very concentrated sources of sugar and carbohydrates, serving size (portion) needs to be reduced if you consume them
- 3. Canned, frozen, and other packaged fruits and juices often come with added sugars and thus it is better to avoid them
- 4. In fact, a fruit is best option for snack for all children with diabetes

In conclusion, almost all fruits and vegetables are good for a person with diabetes if consumed in appropriate amounts as they are rich in fibre and other essential vitamins and minerals.

Recipe

Mixed fruit smoothie

It is yummy summer delight, which would be liked by all children. 1 serving can be easily given as evening snack before play and also can be served as dessert.



Ingredients

- 1 medium banana
- 1 mango sliced
- 1 cup fresh strawberries
- 1/2 cup nonfat dry milk powder
- 1/2 cup apple juice
- 3 cup crushed ice

Directions

- **1.** Place all ingredients in blender container. Blend on high until smooth.
- 2. 1 tea spoon honey and few raisins can be used for toppings
- **3.** If you like sour taste you can use 1 cup thick yogurt instead of milk powder and ½ cup orange juice instead of apple juice.

For 4 children

5



Marriage and type 1 diabetes - by Dr Rishi Shukla

Guide lines for parents of children with diabetes

Whenever any child is diagnosed with type 1 diabetes, many questions arise in the mind of parents. After first few days, when the child is little bit settled, parents ask the doctor invariably." Can my child marry and will their children be fine". Although all parents are worried but worry becomes manifold when the child is a girl child. Invariably we counsel parents, that the child can marry and have long, healthy and productive life. Let me share with you some scientific facts that can bring weight to my words.



Scientific Facts

- Children with type 1 diabetes can live a long healthy life¹. In a 30 year study by the University of Pittsburgh, published in 2012, noted that people with type 1 diabetes born after 1965 had a life expectancy of 69 years. New improvement in diabetes care every year brings a hope that people with type 1 diabetes can even live significantly longer than their siblings and friends because of following healthy and disciplined life style.
- Children with diabetes can definitely have a life partner.
- If the father has type 1 diabetes, the risk is about 1 in 10 (10 percent) that his child will develop type 1 diabetes the same as the risk to a sibling of an affected child. On the other hand, if the mother has type 1 diabetes and is age 25 or younger when the child is born, the risk is reduced to 1 in 25 (4 percent) and if the mother is over age 25, the risk drops to 1 in 100, which is same as that of general population².
- It is possible for all women with diabetes to have babies. The key to have a healthy baby and mother is to achieve very good blood glucose control before becoming pregnant and maintaining that control throughout the pregnancy, which is possible with home glucose monitoring devices and intensive insulin therapy.

All these facts point that a child with type 1 diabetes can marry and can have healthy and normal children

Practical Problems - Practical solutions

- After knowing that the proposal is from a person is having type 1 diabetes, the marriage proposal is rejected I suggest people under my care to reject such proposals and move on.
- Parents want the person with diabetes to marry someone, that the person with diabetes does not like I counsel them that wrong marriages are worse than no marriage.
- Parents and young people with diabetes get disheartened by rejections and comments of society My advice, patience works.

India is a country where until now, marriages are usually arranged by parents and family. Of- course, with changing times the consent of young adults to be married is considered but still marriage is seen as the responsibility of the family. However it is always better to focus on making our children educated, making them self-dependant and rest will follow in due course.

1. Dr. Orchard, Aaron M. Secrest, Ph.D.; Ravi K. Sharma, Ph.D.; and Thomas J. Songer, Ph.D., University of Pittsburgh: Life Expectancy Increasing for Type 1 Diabetics, According to Latest Pitt Research. August 10, 2012. **2.** http://www.joslin.org/info/genetics_and_diabetes.html accessed on 14th April



Diabetes therapy by the ear: Role of the family - Dr Sanjay Kalra

* Derived from articles published in Indian Journal Endocrinology and Metabolism Vol 19/2015/supplement 1

A diagnosis of diabetes affects not only the child, but her or his family as well. Having diabetes entails regular monitoring, visits to healthcare facilities, changes in diet and physical activity patterns and frequent injections. The lifestyle modifications required to implement these facets of management are not limited to the child. Parents, siblings and other loved ones, too, have to alter their routines to fit the (sometimes) rigid demands of diabetes.

Family members make these adjustments happily, realizing that they are part of, and essential for, appropriate diabetes therapy. There, is however, one facet of diabetes management, which all diabetes care providers need to be aware of and follow. This is termed 'diabetes therapy by the ear'. Diabetes therapy by the ear is the phrase used to describe therapeutic patient education delivered with words of comfort. It also refers to empathic history taking, practised with the aim of eliciting determinants of glycaemic control. In a colloquial sense, diabetes therapy by the ear may refer to treatment options, evidence based or otherwise, heard from various sources, reliable or otherwise.

Here we discuss what we can do, as parents, siblings and loved ones, of children with diabetes, to ensure effective diabetes therapy by the ear.

Therapeutic patient education:

Therapeutic patient education is the name given to a continuous process of patient empowerment, done through education and counselling. Provisions of such services have been found to have a therapeutic or beneficial effect on diabetes. While patient education may be thought to be the field of health care providers, all stake holders connected with diabetes shoulder this responsibility. Responsible family members, too, should be proactive in educating themselves and children with diabetes on an ongoing basis. Members of the diabetes care team should be used as a support, in case of doubt or confusion. Thus diabetes therapy by the ear can be administered to, and by, family members of children with diabetes.

Empathic Listening

Diabetes therapy by the ear is a bidirectional process, which involves both listening and speaking. Sharing of information is important to diabetes management: comprehensive history taking is essential of the diabetes care provider to elicit the cause for poor, erratic or unexpectedly aggressive glycaemic control, and pre-empt or prevent such situations. The family member can help in this process by being alert to cues which may suggest hypoglycaemia or may explain the occurrence of poor control. Situations such as examination, emotional stress and menstruation may be linked with fluctuations in glycaemia. Such issues can be identified by family members who are trained in the use of check-lists based upon symptomatology.

This in turn, will be possible only if family members spare time to listen to children with diabetes. Careful listening provides information which is important, yet neglected, and may facilitate improvement in diabetes therapy

Words of Comfort

Growing up is a difficult task. This phase of life becomes more challenging for children and adolescents with T1DM. The distress associated with diabetes can be sometimes overwhelming. One way of negotiating this stress is to provide diabetes therapy by the ear, i.e. words of comfort

Relatives play an important role in modulating the emotions of family members with diabetes. A happy and cordial atmosphere, in which positive coping skills are encouraged, is necessary both within and beyond home and school.

This can be ensured by words of comfort delivered with empathy and understanding, rather than sympathy or sorrow. The responsibility for this, too, lies with the family members as much as it does with the health care providers



External Sources of Information

Families with diabetes are constantly on the search for newer information to help manage and perhaps cure the condition. Such information is freely available from various sources, ranging from the internet to well-meaning neighbours and acquaintances. Sadly, however many of these sources are misleading, and may be harmful. Diabetes therapy by the ear also entails filtering such information and conducting a critical assessment of its relevance. The ear acts as a filter and an audit for information, facilitating the usage of appropriate and ignoring of potentially dangerous information. In this regards, too, family members play an invaluable role for the children with diabetes

Conclusion

Diabetes therapy by the ear is an integral part of diabetes care, in which family has a very important responsibility. Understanding and fulfilling this responsibility is necessary, if we are to help children with diabetes to achieve a happy healthy life.

Where should I inject my insulin?

On the front of my body there are three places I can inject my insulin: the top of my thighs, my upper arms and my abdomen.



Front



Back

On the back of my body there is one place where I can inject my insulin - the fleshy area of my buttocks.

Make sure that each injection is about 2 finger widths from the one done before and to rotate injection sites.

We thank everyone for their kind efforts for implementation of Changing Diabetes in Children program. Please write to us about your views, stories and ideas which can add value to this program and the guardian at **CDICINDIA@novonordisk.com.**

CDiC/0615/8







