



Mishti Guardian

(A CDiC Initiative to Empower the Parents and Families of Children with Type 1 Diabetes)

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Dear Guardians,

Wishing you and your family a very happy new year 2019.

As we move in to the new year, we would like to thank you for your efforts and dedication which has resulted in definitive positive outcomes in the lives of these children. Your passion for changing diabetes in children is commendable.

As you all know, insulin was discovered in the year 1921. In 3 years from now as we complete 100 years of the discovery of Insulin, Novo Nordisk Education Foundation would like to thank Insulin for having saved so many lives of children with type1 diabetes in India through a novel IMPACT India campaign. We are sure this campaign will go a long way to further bring a positive change to the lives of children with type1 diabetes in India and across the globe.

The IMPACT India programme was launched in Delhi on 13 November and aims to improve the level of diabetes care in the country through patients initiatives and healthcare professionals. As caretakers for children with diabetes, let's join together to:

- Help patients attain lower HbA1C levels
- Help patients improve their mental health and quality of life

- Create ambassadors and strengthen patient associations so that we can have meaningful 'Impact India Dialogues' with government stakeholders.

These initiatives call for your leadership and commitment to make a positive and long-lasting contribution. More details about IMPACT INDIA is on the last page.

In this issue, continuing our journey of strengthening knowledge and education among guardians, we have an interesting article on "Management of diabetes in difficult children" by Dr P Raghupathy. Dr Sanjay Kalra writes about the ways in which simple art forms can help a child as well as his or her diabetes care team. We get an inspiring view of life with type 1 diabetes through the story of Shivajyothi, a girl with type 1 diabetes from a small town of Warangal as told to Dr P V Rao. Apart from that we have an infographic on New Year resolutions, which may help each one of us.

We would take this opportunity to congratulate each one of you for the commitment and support you have extended towards 'Changing Diabetes In Children' – Thank you very much!

With lots of best wishes,
Editorial Team



DEALING WITH A DIFFICULT CHILD WITH DIABETES - DR P RAGHUPATHY

Type 1 diabetes is one of the most common chronic diseases of children. Once diagnosed, diabetes is permanent and remains with the afflicted children as they grow. A person with diabetes cannot go on vacation leaving diabetes behind; it needs to be managed all the time. As a parent it is tough to see your child going through all this. But it is even more painful to see a child

having problems and complications which can be largely prevented.

The best way to manage diabetes is to take an active part in the treatment plan and to make informed decisions about various day-to-day situations in life. Understanding diabetes and planning appropriately to deal with it can help your children live long,

healthy and nearly normal lives. Hence our advice to a child with diabetes is always: "Be an informed patient." My team of doctors and educators have helped me in framing certain rules for each child who visits us. Here is a set of 12 things which the child must follow and 12 things which they should not do.

| ✓ | ✗ |
|--|--|
| <p>Insulin</p> <ul style="list-style-type: none"> • Take insulin daily without fail, in the correct dose and at the right time as advised by your Doctor • Rotate the site of taking insulin without fail. | <p>Insulin</p> <ul style="list-style-type: none"> • Do not skip even a single dose of Insulin • Do not take insulin in the same site of injection daily |
| <p>Diet</p> <ul style="list-style-type: none"> • Eat at regular times to keep your glucose levels near normal • Have foods with fiber, whole grains, vegetables and fruits. | <p>Diet</p> <ul style="list-style-type: none"> • Do not skip a meal or undertake fasting, as it will affect your sugars very badly • Do not eat large quantity of any food, avoid consuming excess of sugars, sweets, desserts, candies, jams, honey and fried foods. |
| <p>Exercise</p> <ul style="list-style-type: none"> • Choose any exercise that you like, viz., Walking, cycling, swimming, dancing, yoga etc., & Do it daily • When exercising always keep glucose handy with you to treat low blood sugar levels. | <p>Exercise</p> <ul style="list-style-type: none"> • Do not exercise on an empty stomach • Do not carry out strenuous or long-duration exercises if frequent monitoring is not possible |
| <p>Acute illness</p> <ul style="list-style-type: none"> • Increase monitoring of blood glucose levels • Tell the treating doctor about your child's diabetes and insulin dose. | <p>Acute illness</p> <ul style="list-style-type: none"> • Do not neglect acute illness like viral colds, flu, infections or dental problems as it can increase or decrease blood glucose levels • Do not skip or stop insulin during illness |
| <p>School</p> <ul style="list-style-type: none"> • Inform teachers and school staff about your child's diabetes • Check & ensure availability of emergency diabetes care in school | <p>School</p> <ul style="list-style-type: none"> • Do not hide diabetes from teachers and friends • Do not skip mid meal and insulin doses |
| <p>Traveling</p> <ul style="list-style-type: none"> • Always carry insulin, needles, lancets, glucometer & self-care kit along with you • Carry insulin in a cool pouch in the hand bag that remains with you all the time | <p>Traveling</p> <ul style="list-style-type: none"> • Do not leave your house without carrying your medicines & food items to eat & treat low blood glucose • Do not forget your diabetes identification card |





Although it is understood that no child can follow all these rules all the time, a few rules cannot be broken at all. These are: 1. taking insulin on time, 2. rotating the insulin site, 3. daily exercises and 4. writing honest results in the glucose diary.

If a child continually disregards these four rules, then we take three steps:

1. Counsel the child and family by giving them extra time, education and understanding

at the end of the OPD or on a separate day.

2. Several studies have shown that a non-compliant child may have psychosocial problems*. We refer such patients to psychologists so they can receive the right level professional care.
3. If the child still presents issues, we give the child only one vial of short and long acting insulins, so they need to come again and again to the centre to collect their insulin supplies.

This way we get more opportunities to interact with the child and bring him or her to a better level of adherence.

Sometimes criticisms are raised about my decisions but this is the way I deal with my difficult children.

Adequate management of type 1 diabetes requires an ecosystem of support which includes healthcare professionals as well as disciplined parents and family members.

* Golden MP, Herrold AJ, Orr DP: An approach to prevention of recurrent diabetic ketoacidosis in the pediatric population. J Pediatr 107:195-200, 1985



ART FORMS - DANCING, PAINTING AND OTHER WAY TO COPE WITH DIABETES - DR SANJAY KALRA

From an outsider's perspective, diabetes management should be a cakewalk in today's world. We now have the best of knowledge, insulin, delivery devices, monitoring devices and medicines; and with all this it should be easy to manage diabetes. In the practical world of diabetes, it is not that easy, In fact, it is actually very difficult for children with type 1 diabetes.

Let's look at some of the reasons that a large number of children struggle to achieve optimal control despite being given comprehensive treatment:

1. Poor healthcare-seeking behaviour and lack of adherence on the part of the patient.
2. Clinical inertia, and inappropriate choice of therapeutic regimes and counselling on the part of the physician.
3. Poor psychosocial support from family members or diabetes care providers.
4. Child being stressed by the diagnosis and visit to the hospital.

Whatever the reason, it certainly affects the outcomes leading to uncontrolled diabetes, and poor growth, resulting in a sick child turning into a sick and dependant young adult.

We all know that a child diagnosed with type 1 diabetes needs to take insulin injections for life, and requires daily monitoring and lifestyle changes to keep blood



glucose levels as near normal as possible. These things may sound simple but add up to a huge psychological burden for children with type 1 diabetes.

To help the children overcome this, my team and I decided to add certain art forms to our treatment approach, enabling the child to stay a child while helping in the management of diabetes. Here is our experience.

1. Painting

Benefit to the child – It gives him a chance to relax, enjoy and play with colours.

Benefits in diabetes management – My support staff sometimes discover a child's biggest problems, anger and even desires through these paintings. This helps them in supporting the child in relaxing and in fulfilling her/his goals, thus indirectly providing motivation for better diabetes management.

2. Dancing

Benefit to the child – Most children love to dance. Usually dance improves emotional well-being and provides physical fitness too.

Benefits in diabetes management- Dance is a good form of physical exercise and daily dance classes can be an alternative to daily exercise. Dance involves both upper limb and lower limb movements. This promotes flexibility as well as strength. Certain kinds of dances work to increase insulin sensitivity also along with keeping the nerves, bones and joints fit.

It is well-known that children with chronic disorders including type 1 diabetes have been benefited through coping strategies including seeking social support, physical recreation and seeking relaxing diversionsⁱⁱ.

ⁱⁱ Serlachius, A., Frydenberg, E., Northam, E., & Cameron, F. (2011). A Qualitative Study Exploring Coping Strategies in Youth With Type 1 Diabetes. *Children Australia*, 36(3), 144-152. doi:10.1375/jcas.36.3.144





Shivajyothi
Warangal
Has Type 1 Diabetes

Life insights

“ I want to join the administrative services. I want every child with any disease to get free treatment. ”

Shivajyothi

“Diabetes affects you only when you allow it, but it can never stop you from achieving your goals.”

Shiva Jyothi was diagnosed with diabetes at the age of 11. Shiva was a cheerful girl who was learning gymnastics, music and was active and playful throughout the day. However in 2009, Shiva’s mother noticed that the girl was becoming weak, feeling tired and losing interest in most of the activities which she used to love. Their local doctor told the mother that she was unnecessarily worried and that such changes happen in growing children. Shiva’s mother then took her to a doctor in Hyderabad, where she was correctly diagnosed.

The first few months were confusing as it was difficult for the

family to accept that even young children can have diabetes. To find an alternative to insulin, Shiva’s parents changed doctors and went to many clinics and hospitals. The earnings from Shiva’s father’s street food shop increasingly fell short of the need. In the words of the parents, they were fed up of the disease and constantly worried about the treatment cost. It was becoming difficult for them to buy insulin month on month; monitoring was out of the question. But matters finally took a positive turn when a relative from Hyderabad told them about the DRS CDiC centre.

Shiva Jyothi was enrolled at the centre in November 2011 and is now one of the most diligent and cheerful patients. At present she

is pursuing her BSc in Agricultural Sciences. Shiva Jyothi is not only a bright student, she has also won several awards in music and gymnastics including the “Bal Shri” award in 2014. Shiva Jyothi’s parents say that they could support her education only because they received the best treatment, free of cost, from the DRS center. Shiva Jyothi wants to be a role model for younger children and aspires to support her parents as she grows up. She wants to join the civil services and wishes that every child with a chronic disease should receive free treatment from day one of diagnosis.



Frequently asked questions?



All of us need Insulin

Most of us make it, others need to take it from outside

FAQs

Q1 Should blood glucose levels be kept high to avoid low blood glucose or hypoglycaemic events?

No. It is harmful for the child if blood glucose levels remain high for a long period. Prolonged high blood glucose can lead to life-threatening conditions and complications.

Although hypoglycaemic events can be scary, they are manageable¹. The child or parents should always carry a few hard candies to treat hypoglycaemia in case it occurs.

Some children may experience severe hypoglycaemia, which results in coma or convulsions. In such cases it may be essential to keep the blood sugar levels to a little higher range.

Q2 Is a no-carbohydrate diet good for children as it leads to a lower requirement of insulin?

Carbohydrates are one of three macronutrients (nutrients that form a large part of our diet) found in food – the others being fat and protein. Carbohydrates are the body's main source of energy.

Carbohydrate are a hotly-debated topic, especially in the weight loss world and among people with diabetes. It is essential to understand that we require Carbohydrate and all Carbohydrate are not bad. They are important for growth, health and energy including gaining and maintaining a healthy height and weight.

While most of us need to reduce the amount of sugar in our diet, particularly added sugars, we do still need the carbs found in whole grains, vegetables and fruits.

While it is a good idea to avoid simple sugars, eliminating carbohydrates from the diet could put a child at increased risk of stunted growth and deficiency in certain nutrients and also create various other health problems. It is essential to consult the doctor before making any drastic changes in diet.

Q3 Why do children with diabetes need 4-5 insulin injections per day while others take only 1-2 insulin injections per day?

The goal of treatment is to maintain the best possible level of glucose control by providing the appropriate insulin at the appropriate time to help people with diabetes live healthy, long and near normal lives.

In general, there are two types of insulin treatment plans:

1. Intensive insulin treatment - in this regimen, the child needs to take three or more doses of short-acting insulin along with the main meals per day and one or two doses of long-acting insulin for maintaining the requirement of insulin throughout the day. The doses of the short-acting insulin can be adjusted according to the food consumption and activity levels. Although it seems tough, but this regimen is best for children and adolescents as there is an absolute insulin deficiency and it provides control with flexibility.

2. Conventional insulin treatment – in this regimen, two doses of premixed insulin (short and long acting e.g. 30/70) are given before breakfast and dinner. Children on this regimen need to have a fixed diet at a particular time, with minimum variations in activities, to achieve optimal glucose control. This regimen, seems easy, but it is quite difficult for children to have a fixed diet and activity level throughout the day.

Visit doctor if you observe any of these signs and symptoms



¹. Diabetes UK. Children and diabetes. Available at: [www.diabetes.org.uk/Information-for-parents/Accessed July 2012](http://www.diabetes.org.uk/Information-for-parents/Accessed%20July%202012).



NEW YEAR RESOLUTIONS

Making a New Year's resolution for one's health is one of the most important things that we can do for ourselves. A few changes in one's lifestyle and food habits along with proper medication and monitoring can help a person with or without diabetes lead a normal healthy life. Let us choose any 3 activities and do it together so that it becomes a habit in 2019.

Activities for Good Health - Choose any 3



More exercise



More Veggies



Less time on digital devices



Visit the doctor on time



Monitoring blood sugar regularly



Write correct values in diary



Not skipping insulin doses



Having breakfast daily



Going for annual health check-up

Choose a blissful life and love yourself

MAKE YOUR OWN PLATE

- Diet of a person with diabetes is the same as a healthy balanced diet
- Moderation is the key to good health
- Limit intake of empty calories foods.
Eg: cookies, soft drink, candy, chocolate, jam, cake, namkeens, samosa.




IMPACT INDIA PLEDGE



Impact India is an initiative to reach out to our key stakeholders in the healthcare setup, patient communities and the society at large to make robust efforts to bring about a change by reducing HbA_{1c} by 1%. This change will be visible, measured, acted upon and reassessed for further improvement. The Novo Nordisk Education Foundation will lead this effort with the help of like-minded doctors and patient associations will work in collaboration and bring about a change.

We hope that most of you must have taken a pledge for making a change, if you have still not taken the pledge, please take a minute to do so.

It can be taken either by going to website or scanning QR code below. Thank you for joining the movement.



world diabetes day
14 November

6 TIPS FOR PARENTS OF CHILDREN WITH TYPE 1 DIABETES

- Acknowledge the child's feeling
- Caring for a child with type 1 diabetes requires effort and understanding. Ask for support
- Take time and meet other children and families in similar situation
- Involve the child in their treatment from day one
- Opt out from words such as "bad sugar", "terrible situation" and other negative words
- Never forget that we all are human beings and mistakes are going to happen

LEARN, RELEARN and keep on LEARNING

[Click here to take the pledge](http://nnef.in/impact-india)

<http://nnef.in/impact-india>



Scan the QR code to see the video.