

# Best practices from Changing Diabetes® in Children India

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### ABSTRACT

It is estimated that India alone has 70,200 cases of T1DM, with an annual increase rate of 3–5%.<sup>[2]</sup> Despite being the most common chronic disease in children and adolescents, T1DM does not receive the attention it requires. Many children die of undiagnosed diabetes or shortly after diagnosis because of poor blood sugar control. Everyone with type 1 diabetes requires insulin from the beginning.<sup>[3]</sup> Continuous management, comorbidities, and chronic complications place a heavy psychological and economic burden on the whole family. Challenges in India are at many levels, right from diagnosis, health-care delivery, availability of trained physicians, infrastructure, insulin, and monitoring and providing psychosocial support. The Changing Diabetes® in Children (CDiC) Programme is a part of Novo Nordisk's Access to Diabetes Care strategy and builds on the undefined cornerstones in the right to health. With an aim to improve the health condition and quality of life of the children with diabetes, this program was started in 2009. Globally, the program is operational in nine underdeveloped and developing countries including India and there are a total of >14,000 children under the care of the CDiC Programme. This global program was launched in India in 2011 by late former President Dr. APJ Abdul Kalam through Novo Nordisk Education Foundation. It has a pan-India footprint with 21 established centers in government hospitals and specialized clinics and >4000 registered children. Apart from providing essential care which includes free doctor consultations, providing insulin, and monitoring insulin, CDiC is also working in other key areas in type 1 management, namely, (1) diabetes education – with specially designed diabetes education tools, for children, parents, siblings, and other caregivers, (2) awareness and capacity building – advertorial series for general public and special accredited trainings for doctors and other health-care professionals, and (3) communication for all stakeholders – periodic CDiC newsletters and Mishti Guardian.

**Key words:** Changing Diabetes® in Children India, diabetes education tools, diabetes in children, type 1 diabetes

## INTRODUCTION

Type 1 diabetes mellitus (T1DM) is one of the most common pediatric endocrine and metabolic illnesses.<sup>[1]</sup> It is usually diagnosed in children and young adults. Only 1–5% of people with diabetes have this form of the disease;<sup>[4]</sup> rest have type 2 or other types of diabetes. It is a chronic, T-cell-mediated autoimmune disease, in which the body destroys the insulin producing beta cells in the pancreas, leading to progressive and irreversible failure of pancreas to

secrete insulin. If not treated with insulin, this condition can cause hyperglycemia, ketoacidosis,<sup>[5]</sup> and even death.

## CHALLENGES FOR CHILDREN WITH DIABETES

It is essential for child to learn to take self-insulin injection, to monitor sugar levels at home, and to adjust diet and

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exercise to keep blood sugar levels near normal. Diabetes self-management is a continuous job (24 × 7) and cannot be left at its own at any point of time. Education and counseling about diabetes and its management are very important. Initially, it is a means of sharing responsibility between health-care professional (HCP), the child, and its family. In the long run, this means ability to manage diabetes in varying situations of day-to-day life. Diabetes in children has a huge psychosocial impact as children with diabetes face discrimination and sometimes also limited social relationships.

Health care in India is mostly an out-of-pocket expense. This results in a huge financial burden on affected households and it can push many families into poverty. This often leads to many children from economically poor background to lose their lives to type 1 diabetes mellitus (T1DM). On the other hand, if properly treated, children with type 1 diabetes can grow like normal individuals, be productive, fertile, and long-lived adults. It is therefore essential that childhood diabetes is recognized as early as possible and treated adequately. In this scenario, Changing Diabetes® in Children (CDiC) Programme has incorporated activities essential for improving awareness, self-management, capacity building, and over all better treatment for these children with type 1 diabetes. While implementing these activities, there are some of the elements which are getting total involvement of the children and other key stakeholders. These best practices can be categorized under key two heads, namely, (1) patient education tools for better understanding and self-reliance and (2) HCP training for capacity building.

## PATIENT EDUCATION TOOLS

These tools help children understand their diabetes better and give them an opportunity to self-manage their condition [Table 1].

**Table 1: List of child-friendly educative materials**

Educative tools	Tool description
Mishti – Storybooks	Series of 4 storybooks (English and nine Indian languages)
Video	Mishti educative video (English, Hindi, and Kannada)
Educative toys	Novo Nordisk Teaches to Take Insulin Doll/snakes and ladders/hypo kit/healthy plate/diet snack box
Educative posters	Know the symptoms, hypoglycemia, hyperglycemia, insulin and glucose monitoring, make your own plate, foot – door hanger
Educative visual aids	Type 1 diabetes education, Novo Aid Booklet, makes a healthy change folder
Educative leaflets/informative newsletter	Know about carbs, diets leaflet, do's and do not's series/changing diabetes in children newsletter, Mishti Guardian
Educative monitoring tool	Glycated hemoglobin wheel and chart, body mass index chart

- Mishti is a story of a little girl with diabetes who shares her journey with type 1 diabetes. Four booklets of the series have been released so far:
  - Mishti-1 speaks about basic understanding of type 1 diabetes
  - Mishti-2 is a story about Mishti participating in sports day and attending Christmas party. These includes instructions for the child with diabetes while doing any exercise or participating in any sports activity
  - In Mishti-3, the story revolves around Mishti going to school trip. This includes instructions for the child with diabetes to be followed while traveling
  - Mishti-4 has Mishti talking about things to be followed during sick days.

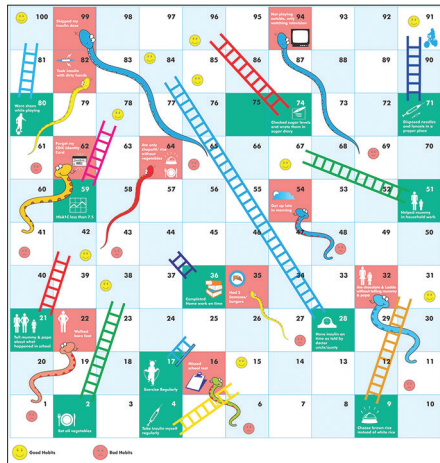


- Novo Nordisk Teaches to Take Insulin (NOTTI) Doll is a soft, unbreakable, easy to carry educational toy, designed as a diabetes education tool to teach about correct insulin taking technique. The purpose is to help the children learn how to take insulin and how to rotate the site of injection. NOTTI Doll also helps the physician to initiate conversation, to practice taking injection, and to become well versed in self-injection.



- Snakes and Ladders is another diabetes education tool which is designed from the old conventional

board game. While playing this board game, the child learns the basic “do’s and do not’s” of diabetes. In this game, each square represents a habit; some of them are applicable for all children and a few are applicable specifically for children with type 1 diabetes. The square at the base of a ladder is represented by a good habit/the do’s, which, like ladders will take you higher/ahead in life. On the contrary, the square at the head of a snake is represented by a bad habit/the do not’s, like snakes bad habits create hindrance in moving ahead.



4. Hypo kit: This helps the child prevent hypos and consists of a snack box and water bottle to help them carry something to eat and water to drink.
5. Make your own plate: This educational material is made on physical demonstration of a plate containing balance diet and exchange of various food items within each category. It has been a great hit among the children as they can decide what they want to eat and in how much quantity they can eat that particular food. It is also perceived as a great tool by educators keeping in mind the cultural and culinary diversity of India.



6. HbA1c calculator: This calculator helps child and their parents convert HbA1c readings into average blood glucose.
7. Make a healthy change folder: As the name suggests, this is an input consisting of healthy recipes, lifestyle tips on diet, exercise, insulin, and monitoring. It also contains insulin site rotation aid.
8. Know about carbohydrates: It is a leaflet prepared to give understanding about carbohydrates in Indian context.

## UNIQUE FEATURES AND BENEFITS

- These educational toys have been made keeping in mind cultural and ethnic issues prevalent in India
- All these materials have been made in ten Indian languages to cater to all the children across the country
- Helps in breaking the silence between child and doctor or educator
- Creating friendship rather than strict doctor-patient relationship which has been taught knowingly or unknowingly to the child
- Reducing stress of unknown and being alone for the child
- Understanding what diabetes is
- Planning for diabetes self-management in various situations of life
- Keep the learning with them to reread and relearn
- Motivating the child for self-care
- Reinforcing correct diabetes care essentials.

## ACCREDITED HEALTH-CARE PROFESSIONAL TRAINING

Due to huge burden of management of type 2 diabetes, most of the treatment protocols are focused on type 2 diabetes with less or not much information on type 1 diabetes. The CDiC Programme along with 21 center directors is helping in overcoming these challenges faced by HCPs in multiple ways, namely,

1. Accredited HCP trainings
2. Creation of ready reference booklet on type 1 diabetes for HCPs
3. Printing of ISPAD’s booklet on management of children and adolescents with diabetes.

To create interest about the special needs of T1DM among qualified HCPs, 2742 doctors and 1445 paramedical staff have been trained via the “T1DM workshops,” conducted across the country. Along with medical aspects, psychosocial and behavioral management of children with T1DM are also discussed. To make this

learning more systematic and standardized, a curriculum with power-point presentations for training HCP was prepared with the help of center directors. Depth of these programs can be understood by going through this curriculum.

Section 1: Overview of diabetes with special focus on diabetes in children, clinical features, investigations, management essential, and short- and long-term complications and their prevention.

Section 2: Lifestyle management of type 1 diabetes – diet and exercise for normal growth.

Section 3: All about insulin site, technique, regimes, dose adjustment, and monitoring.

Section 4: Coping skills to be taught - parents counseling, hypo- and hyper-glycemia, and sick day management dealing with medical, physical, psychological and social environment.

Section 5: Needs of specific age group, infant and toddler, school-going children, adolescents, and transition to adulthood.

Section 6: Managing type 1 diabetes in specific situations such as traveling, party, festivals, fasting, and surgery.

Since accredited workshops generated more interest among HCPs to get involved in such teaching sessions, mainly because it gave them credit hours and was also viewed to be of higher standard and quality, we decided that all CDiC type 1 updates will be accredited by the medical councils. By this approach of training HCPs

and educators and conducting it more as a practical learning and workshop, CDiC hopes to improve the overall management of children with diabetes in India in the coming years.

## UNIQUE FEATURES AND BENEFITS

- HCP training with accreditation from the local medical body
- Involvement of top key opinion leaders
- Specific focus only on type 1 diabetes
- Discussion of psychosocial aspects along with medical aspects
- Education on type 1 diabetes, keeping in mind Indian scenario – out-of-pocket expenses, poor socioeconomic status, cultural and ethnic taboos.

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## Conflicts of interest

There are no conflicts of interest.

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