

“Living with type 1 diabetes: Life story of Pallavi”

Sir,

This is an extract from the experience shared by Pallavi and her parents to Udaiya Sangavi, coordinator from MV Hospital, Changing Diabetes in Children (CDiC) center, Chennai, Tami Nadu, India. We would like to share some of the social aspects of type 1 diabetes in children through this communication.

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

BRIEF BACKGROUND

Pallavi was born and brought up in a village in Arakkonam, Tamil Nadu, India. Her father worked in a private company but left his job a few years back. Her mother works as a teacher in a private school. She has one elder brother who is unemployed. At present, Pallavi is pursuing 2nd year Bachelor of Science (B.Sc.) in a government Arts and Science college near her home. She has a good passion for education.

WHEN AND HOW THE FAMILY CAME TO KNOW ABOUT PALLAVI'S TYPE 1 DIABETES

Pallavi was diagnosed with type 1 diabetes 3 years ago. This happened 2 weeks before her 10th standard examination. According to her, at that time she felt very weak and suddenly lost 4 kg in 1 week. Her parents thought that she was becoming weak because of her hard work and stress before the examination. So they asked her to take some rest

and to eat proper food. But her situation kept worsening. Her parents took her to a nearby government hospital because of severe abdominal pain. After examination and diagnostic tests, they declared that she had high blood sugar levels. Her random blood sugar levels were 648 mg/dL at that time. She was immediately admitted in the hospital. The doctors told them that Pallavi needed insulin as her condition was serious but fortunately she had mild ketoacidosis. She was discharged from the hospital 2 days before her examination.

INITIAL REACTIONS OF FAMILY

Her whole family was shocked and did not know what to do. Though Pallavi's condition was diagnosed and she was given treatment, the family and the child were not educated on type 1 diabetes. They did not know what was happening to her. Everyone in her family was upset about her health, about the requirement of insulin, her examination, and also about how they were going to spend for her medical expenses.

Pallavi was very confused as to why it happened to her and how she was going to face her board examination, which was a main part in her life. She had not prepared well for her examination.

ISSUES AND BELIEFS

No one in the family knew about type 1 diabetes and the importance of insulin. She was reluctant to take injections because of pain and its discomfort. Her parents were also not aware about the importance of insulin injection. At that time, they thought that it was a wrong decision in

allowing the doctors to start insulin. When she refused to take an injection, they did not encourage her to take insulin. Her situation got worse, and she started losing consciousness. Then her parents took her to another doctor. This doctor explained them in detail about type 1 diabetes and also about how insulin was life for her. He also taught Pallavi how to take insulin herself.

JOURNEY OF LIVING AND LEARNING TO MANAGE DIABETES

Pallavi was adamant on not taking insulin. She thought that taking food increased the sugar levels. So, she avoided intake of food and also insulin for 1 whole day. Everyone at her home begged her to take food and insulin but she did not obey. She started shivering and fainted in the evening. Her parents rushed her to the hospital. After repeated advices from the doctor and parents, she took food.

As soon as she completed her examination, through their relative in Chennai, Tamil Nadu, India she visited the MV Diabetes CDiC center at Royapuram, Tamil Nadu, India and got enrolled in the CDiC Program. She started getting free insulin, glucometer, diet chart, and regular diabetes education. Repeated counseling was given by the doctors, staff nurses, and diabetes educators. Diabetes education camps had a very big influence on her. At present, Pallavi and her family members have learnt many things on the management of diabetes such as hypoglycemia (low blood sugar), hyperglycemia (high blood sugar), and also about the right food intake and insulin usage for good blood control.^[1]

INCIDENT, WHICH DOCTOR WISHES TO SHARE

When she came first to the center, her hemoglobin A1c (HbA1c) was 13.9%, and fasting and postprandial blood sugar levels were between 350 mg/dL and 500 mg/dL. She also had elevated low-density lipoprotein (LDL) and total cholesterol levels. Then she was prescribed a statin, along with insulin. She was given a dietary consultation, and asked to exercise more frequently. She was advised to regularly monitor her blood sugar level and then asked to come the next month.

During her next visit, on examining her diary it was found that blood sugar levels were still in the higher range. On enquiring whether she was taking insulin properly as prescribed, she told that she was skipping her dosage and that she was doing so because she did not want to live with this condition. She was counseled by a specialist, made to meet children in her age group, and her parents were advised to take care of her and monitor her.

ENVIRONMENTAL FACTORS INFLUENCING CHILD'S LIFE

Family

Pallavi's family is always worried about her. Her father takes care of her in the absence of her mother. Her parents are very caring and supportive. Her parents keep on encouraging her to study. It was her father who supported her in gaining confidence back in herself when she got very less marks in the 10th standard.

Friends

Initially, when she was diagnosed in the 11th standard she always remained low, tired, worried, and not confident. She also avoided meeting and playing with her friends. This caused a poor relationship with her friends. She felt very lonely until her mother invited her friends to home 1 day. Then, her friends came to know about her diabetes. After that, they started being very supportive and started helping her when she could not take notes in class and in many other ways. At present, she shares a very good relationship with them.

School

Her school principal initially refused to give her admission to the 11th standard, as her marks were less in the final examination. Later on, after requests from her parents and the doctor and understanding Pallavi's health condition, the principal considered her marks in the preboard tests and gave her admission. Her class teacher understood her and encouraged her and this resulted in good marks in her 12th standard. She secured 1,025 marks.

College

Most of Pallavi's college mates and lecturers do not know about her diabetes. Only her best friend knows about her diabetes. Pallavi feels that she is at present a grown-up girl and can now manage her diabetes on her own. She attends college regularly and also has a good attendance record.

Medical center

She listens to all the instructions given by doctors, educators, and dieticians. She tries her best to follow them and at present she has a good control over diabetes. She loves to do yoga, which she learnt from the medical center and does it regularly at home.

Changing diabetes in children

From the time she got enrolled in CDiC, she has been regular in the follow-up visits. She is regularly monitoring her glucose level at home using the strips and glucometer given in the CDiC program. She is one of the type 1 diabetic patients among the CDiC children who has good

control of her diabetes; HbA1c ranges 6.8-7.1% over 1 year of time. Her parents feel that this holistic program and treatment is of great help to them without which they would have not been able to support Pallavi. It is only because of this program they have known so much about diabetes and are able to manage diabetes at home.^[1]

Camps

Pallavi loves to come to the camp. She has made many friends with type 1 diabetes in the camp. She is motivated by seeing many small children present in the camp. She wants to be an inspiration for them. She actively participates in games activities in the camps.

DOCTOR'S INSIGHT

The initial 1 year after diagnosis is most crucial. It is the time when the parents are in great shock and a child tends to absorb many negative talks and reactions in the mind. At this time, the role of the doctor and the team as a friend, counselor, and guide is most important. It was very easy to scold Pallavi for what she was doing but my team made her understand that life is possible and beautiful even with diabetes. It was she who mended her way and made us feel proud of her and ourselves.

IMPACT OF DIABETES ON LIFE

Diabetes has affected the life of the child and family in many ways. Many times, they refuse to go out to relatives' homes and to functions because everyone starts talking and showing their pity about Pallavi's condition. This makes her feel bad about herself. Also, she thinks that because of her diagnosis of diabetes, she got very less marks in the 10th standard and was not allowed to take up the science group in her 11th standard, which ruined her ambition to become a doctor.

AMBITIONS AND ASPIRATIONS

She wants to pursue higher studies and wants to become a teacher. She also wants to learn more about diabetes management, and give free service as a diabetes educator to children like her.

CONCLUSION

- Diagnosis of diabetes in the child has immediate and profound physical, psychological, social, and financial impacts on the child and the entire family.
- The family and the child can be in any state of mind – Shock, denial, anger, and depression, which is manifested in their behavior toward health care professionals.
- In our busy schedules, we forget that diabetes is very new for them and before accepting it, we need to deal with their fears, grief, depression, anger, and every other issue in a patient-friendly approach.

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Access this article online	
Quick Response Code:	Website: www.joshd.net
	DOI: 10.4103/2321-0656.176581

How to cite this article: Viswanathan V. "Living with type 1 diabetes: Life story of Pallavi". *J Soc Health Diabetes* 2016;4:47-9.