

# Thalassemia & Sickle Cell Society report

### Impacting Emotional Behavior



**Abdul Fassi** 

Famida had 3 kids. 1st Son was born in 1993. 2<sup>nd</sup> son was born when the elder son was just 1 year old. This son eventually passed away in his 6th month due to lack of Blood. Family had no idea why the blood count dropped.

Later Famida gave birth to another son after 3 vears they named him Fassi. Just after few months of his birth his body started turning pale & white. Doctor advice to take blood transfusion due to lack of Blood in the body. Fassi was diagnosed with thalassemia!

Most of the children with Thalassemia have psychological problems and poor quality of life. They usually suffer with anxiety-related symptoms, emotional problems, depression and conduct problems.

"Fassi was born fair and healthy" he had good weight, even upto the age of 8, his mother would carry him on her shoulders due to the affection and love and also the feeling of sympathy towards his ill health. His Mother in her distress said, "My prayer is that no child should ever get such a disease & no mothers should ever come across such a situation in life.

Fassi was given free blood but parents could not afford expensive iron chelating drugs (Iron Chelating Drugs helps in reducing excess Iron that comes along with the new blood transfused). Due to the access Iron in the body deposited over 20+ years Fassi fainted and his heart beat increased. A timely advice by the TSCS staff and Dr. Suman in getting him admitted to the hospital and doctor's attention at the right time could save his life. Now for almost one year Fassi is on Iron chelating drugs and that had helped improve his life.

Children with chronic illnesses are vulnerable to emotional and behavioral problems. The rigors of treatment and frequent absence from school had brought huge impact on Fassi's emotional and interpersonal behavior. He is also a victim who is struggling in the process of acquiring knowledge and understanding through experience, and senses and finds himself different from others who are striving for independence and identity.

Thus each age group has problems unique to that stage of development. Children with thalassemia are likely to have psychological problems like stress & anxiety and Fassi is no exception.

Parents have to say that today if Fassi is alive is just cause he is well taken care in TSCS. They are thankful to Doctors for their timely intervention in getting Fassi revived back to life.

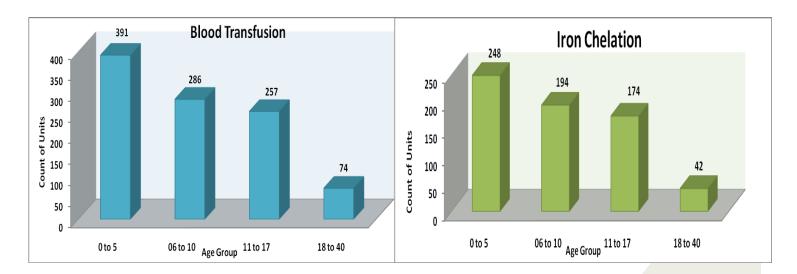


#### Signs of Depression



- Persistent sadness, lasting two weeks or more.
- Loss of interest in your favourite
- Finding no fun or enjoyment in
- Loss of self-confidence.
- Feeling guilty, bad, unlikeable, or not good enough.

## **Transfusion Details**



Total number of patients for the month of February 2020 including all patients group were 1008 some patients were given 2 units of blood, the total units provided where 1259

HPLC at Society Couples/siblings	CVS referred to CDFD	New registrations	Splenectomy
44	5	16	NIL

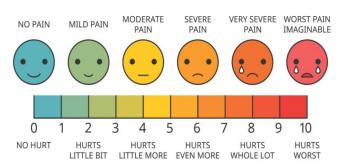
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#### Emotional factors: How your child feels about being in pain

How a child expresses pain is always modified by their emotions. To get a sense of how and to what extent emotions will influence pain, ask yourself the following questions about your child:

- Is there stress and anxiety in anticipation of pain?
- Does pain create a heightened distress?
- Is there a fear of continuing pain or pain without known cause?
- Does the pain create situation-specific stress, for example at school or during social activities?
- How much frustration exists due to new limits on activities?
- Are there underlying anxiety and depression issues with your child?

#### **PAIN MEASUREMENT SCALE**



#### Behavioural factors: What you and your child do to lessen pain

Behavioural factors influencing pain comprise what the child, their parents and other caregivers do about pain. These include:

- responses to pain-induced stress
- the use and effectiveness of pain-relieving therapies such as relaxation and distraction
- how others around the child react to a painful episode

Particulars	Units
Sensitisation programmes organised	25
Blood donation camps	19
Collected units of blood	1529
Units provided to thalassemia + general free issues	1259
GENERAL PAID ISSUES	179
FFP ISSUES	981
SDP	3



#### Thalassemia & Sickle Cell Society

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