



Baby Muhd at 7 months old

Bringing the family closer

BABY MUHAMMAD Patient

Muhammad lies soundly asleep on a pillow. His mother cradles the pillow in her arms, and sings a lullaby. Other family members gather around. “Every gift that comes from above is good,” says Encik Azrul Fahsha, Muhammad’s father. “We have many things to be thankful for.”

Muhammad is 7 months old and born in Muar, Johor. He is the youngest of five children. During birth, the bones in his arm and leg were broken. The doctors referred him to specialists in KL, where his parents found out about Osteogenesis Imperfecta (OI, otherwise known as “Brittle Bones”). They had never heard of the disease before. At the same time, Muhammad was also referred to Hospis Malaysia.

“Overnight, our world turned upside down. The ante-natal scans showed that he was a normal baby, and we didn’t know how to react,” says Encik Azrul. “But we knew we had to move to KL so Muhammad could receive treatment.”

Moving to the capital wasn’t an easy decision. En Azrul had to find a new job, new house and new schools for the children. All while finding out about a new disease called OI, and wondering if he will ever be able to hug his little boy.

“I agreed to be referred to Hospis Malaysia not knowing what to expect,” says Puan Rosilah, Muhammad’s mother. “Within 24 hours, a doctor and nurse dropped by. We had so many questions for them!”

Palliative care nurse Nisha was assigned to look after Muhammad and the family.

“I didn’t know how to handle Muhammad at first. How to bathe him, how to feed him, how to change his tubes. I would call Nisha every two hours,” says Puan Rosilah. “There were many frantic calls after midnight, and every time, somebody would answer the phone and provide the necessary assistance.”

Nurse Nisha looks calm, as if she’s done this a hundred times before. A few months ago, she recommended that Hospis Malaysia extended the use of one of its paediatric oxygen concentrators to little Muhammad to enable him to breathe better.

“Do you “sayang” (love) Muhammad?” asks Puan Rosilah to her other children. The children didn’t have to answer. As Puan Rosilah is adjusting Muhammad’s tube, his brother Rayyan distracts him by dancing and singing. Nur Rusydina gently strokes his forehead, while the other two busy themselves making everybody comfortable.

Encik Azrul looks wistfully at his family. “This little gift has brought us closer together.”



How Hospis Malaysia is supporting:

- Caregiving support
- Navigating the family through treatment options
- Symptom control