

'I just want to see my grandson grow up': Ex-liver transplant patient's family seeks donor as organ fails



Mr Sulaiman Mussein, 61, with his wife, Mdm Radhiah Abdul Rahman, 61, at their place in Tampines on May 6, 2021. ST PHOTO: ARIFFIN JAMAR

Timothy Goh

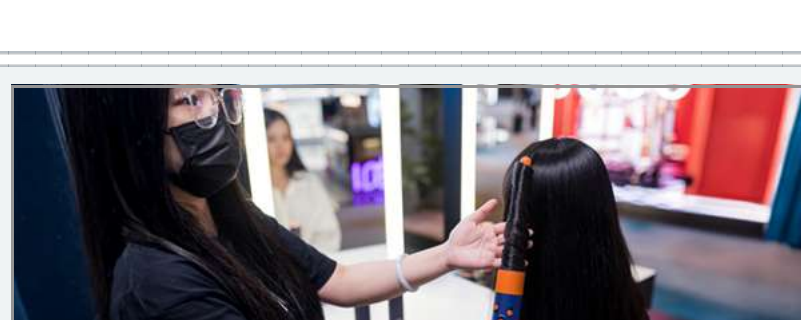
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SINGAPORE - It was the middle of the night, in August 2019, when Mr Sulaiman Mussein awoke with a start, stumbled to the bathroom and threw up.

"I thought I just vomited only - I never turned on the light. But then my wife did and said 'abang, got blood'," recounts the 61-year-old in an interview with The Straits Times on Thursday (May 6).

The former cabby was still coughing up blood when he arrived at the National University Hospital (NUH).



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The next morning, a doctor delivered the bad news: He had liver cirrhosis, a late stage liver disease where the liver becomes scarred and shrunken.

This was not Mr Sulaiman's first brush with such bad news.

In 2004, he visited NUH with acute hepatitis B flare, where certain enzyme levels in the liver rise abruptly, causing a patient's hepatitis condition to worsen, leading to liver failure. Mr Sulaiman had been found to have liver failure.

That year, his family's struggle to get him a liver transplant made headlines. After an agonising wait, a suitable donor was found and Mr Sulaiman, who was 44 at the time, was given a new lease of life.

His case also prompted a change in national health policy, with the Health Ministry announcing soon after that patients waiting for transplants from a living donor would be allowed to pay public hospital rates even if their operation was carried out at a private hospital.

And for the next 15 years, it seemed like all was well.

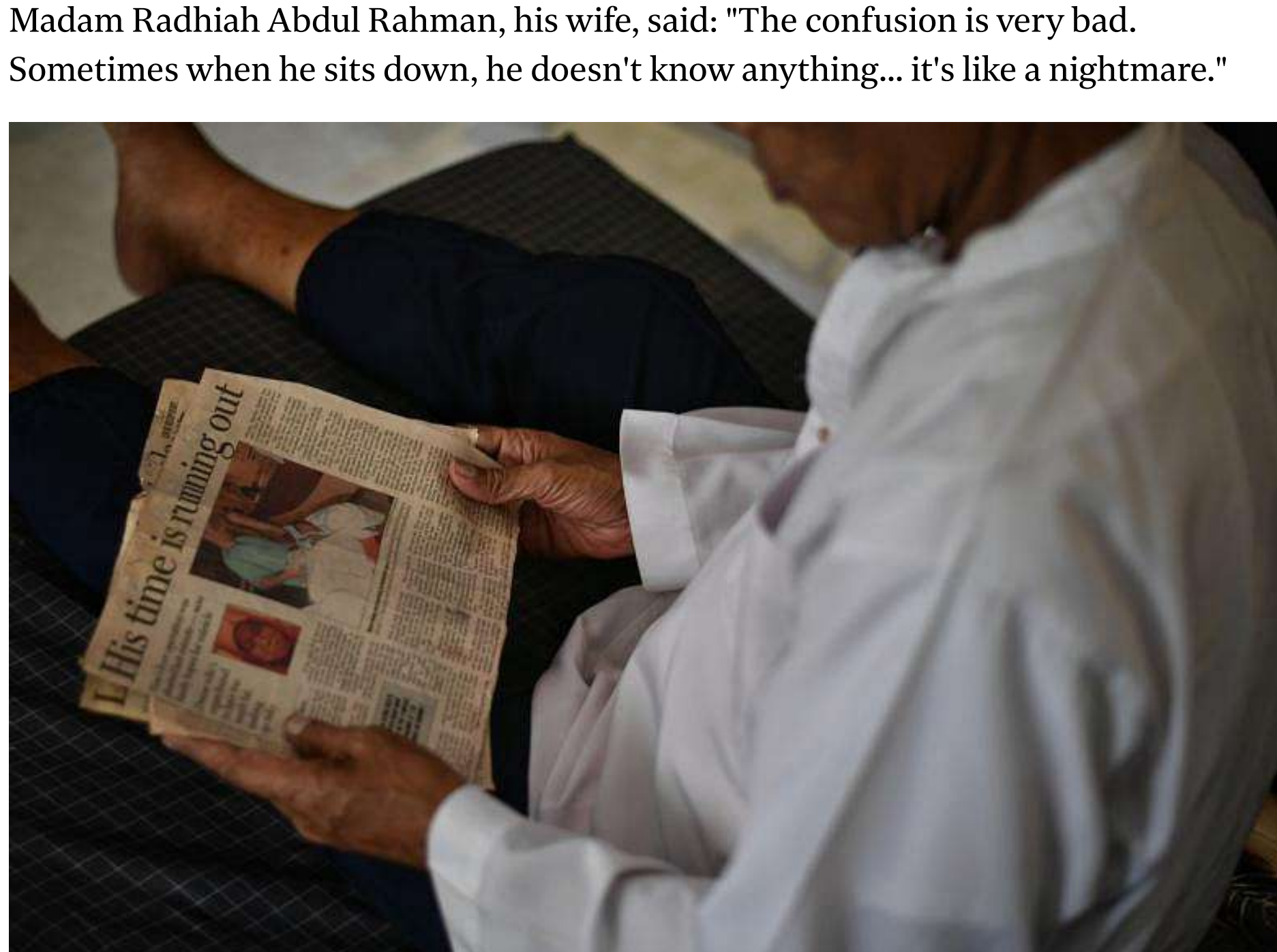
He went back to work, becoming a taxi driver at one point, and spent weekends exercising or just hanging out with his friends.

Everything changed after that August 2019 night.

Mr Sulaiman now needs help to move around and has to visit the hospital several times a week. He must also follow a strict diet to manage his diabetes, which can affect his liver.

In addition, he has episodes of confusion at least once a month, where he does not know where he is, cannot recognise people and even loses control of his bowel movements and motor functions.

Madam Radhiah Abdul Rahman, his wife, said: "The confusion is very bad. Sometimes when he sits down, he doesn't know anything... it's like a nightmare."



Almost two decades ago, Mr Sulaiman Mussein made headlines with drama surrounding his liver transplant. ST PHOTO: ARIFFIN JAMAR PHOTO: ST

The housewife, also 61, added: "It's not easy for the family. Sometimes in that state he doesn't want to go to the hospital, he doesn't want to leave this house."

As a result, he cannot be left on his own.

The couple live with their 30-year-old son, who is their household's sole breadwinner, in a flat in Tampines. Their 33-year-old daughter lives elsewhere.

Associate Professor Shridhar Iyer, the surgical director of the Liver Transplant Programme at the National University Centre for Organ Transplantation (NUCOT), said these episodes of confusion are the side effect of a treatment Mr Sulaiman is taking to keep him alive, known as a transjugular intrahepatic portosystemic shunt (Tips).

It involves making his blood bypass his liver to decrease the pressure in his blood vessels.

However, because the liver helps to process toxins in the blood, these toxins now build up in Mr Sulaiman's body, affecting his brain.

Prof Shridhar, who is also a senior consultant for liver transplantation, added that there is a risk of the confusion turning into a coma.

As a result, Mr Sulaiman is forced to move his bowels two to three times a day in order to purge the toxins from his system, sometimes even requiring the aid of a suppository laxative.

But Tips is not a long-term solution.

Prof Shridhar said: "It's a therapy which allows patients to carry on until definitive treatment - in this case a transplant - is available."

He added that if Mr Sulaiman does not get a liver transplant in the next three months, he has a 20 per cent chance of dying. This will rise to 30 per cent in a year's time.

A glimmer of hope had appeared at the end of 2019, when the family was informed of a potential donor.



Mr Sulaiman now needs help to move around and has to visit the hospital several times a week. ST PHOTO: ARIFFIN JAMAR PHOTO: ST

"It felt like I had won a million dollars," said Mr Sulaiman. But his hopes were dashed when, after being brought to the operating theatre, it was found that the liver did not match.

"He was very depressed," recalled Madam Radhiah.

In October the next year, in a bid to save his father, the couple's son offered his liver. But it was found to be unsuitable.

And at the start of this year, the family was told to be on standby as another potential donor was found. However, the next morning, they were told it had been given to another patient who needed it more.

Prof Shridhar explained that a patient's priority in the wait list for a liver is based on a model for end-stage liver disease (Meld) score. Under this model, those with a higher score have a higher chance of dying if they do not receive a transplant.

Mr Sulaiman's score is currently 18 out of 40, which is "higher than average".

But even if a live donor were to step forward, it would be a complex operation, because Mr Sulaiman has already had one liver transplant done, said Prof Shridhar. "His best chance is to get a full liver from a deceased donor," he added.

But the rate of donation of organs from deceased donors is low here - about 6 per million population. This is higher than most Asian countries, but much lower than the 10 to 40 per million population in Western countries.

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In 2019, the average waiting time for a liver from a deceased donor here was 12.4 months. Last year, there were 54 people on the wait list for a liver.

But despite the setbacks, Mr Sulaiman is trying to remain positive.

Asked how he felt about needing a second liver transplant, he said: "Whatever happened (to me), there must be something good at the back of it."

He says with a small smile that he has gotten closer to his wife and son since falling ill, and that he is no longer as angry as he used to be when he was working as a cabby.

"I just want to live. I want to see my grandson grow up."

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Former liver transplant patient's family seeks donor

Without a transplant in next three months, man with liver cirrhosis has 20% chance of dying: Doctor

Timothy Goh

It was the middle of the night, in August 2019, when Mr Sulaiman Mussein awoke with a start, stumbled to the bathroom and threw up. "I thought it was just vomit – I didn't turn on the light. But my wife did and she said, 'there's blood'," recounted the 61-year-old in an interview with The Straits Times on Thursday.

The former cabbly was still coughing up blood when he arrived at the National University Hospital (NUH).

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Mr Sulaiman Mussein, with his wife, Madam Radhiah Abdul Rahman, both aged 61, in their Tampines flat. Despite all his setbacks, Mr Sulaiman is trying to remain positive. ST PHOTO: ARIFFIN JAMAR

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