

Stories by YUEN MEIKENG  
meikeng@thestar.com.my

THE signs aren't obvious in the beginning. And that is why some call it a silent disease.

But it isn't a time to keep quiet about chronic kidney disease (CKD), which strikes nine out of every 100 Malaysians.

The overall number of patients – from stage one to five – is currently between two and three million, but the numbers are expected to rise.

Most patients in stage five, known as end stage renal disease or kidney failure, depend on dialysis to carry on with life.

But while there are 40,000 dialysis patients now, the number is projected to more than double to a whopping 106,249 in 2040 if no effective remedies are in place, based on a recent study.

The large number of dialysis patients has made Malaysia the top seventh country with the highest dialysis treatment rate in the world, based on the study titled "Forecasting the Incidence and Prevalence of Patients with End-Stage Renal Disease in Malaysia up to the Year 2040".

However, many kidney patients in Malaysia are still hoping for the alternative solution – a kidney transplant.

In fact, most of the 20,000 people on the organ transplant waiting list are in need of kidneys.

The problem is that while organ pledges remain low, the number of medical professionals, including surgeons and supporting staff, that can conduct transplants are less than ideal.

Health Ministry deputy director-general Datuk Dr Jeyaindran

# Don't kid with kidney failure

Star  
4/14/2017  
mls 18-19

The number of dialysis patients will more than double by 2040 if chronic kidney disease is not properly addressed. As part of the remedy, the Government plans to boost organ transplants in the country.

One plan is to double the number of "organ retrieval" teams, or teams of medical staff in charge of retrieving organs from those who have pledged their organs upon death.

Currently, Malaysia only has two of such dedicated teams – one from Hospital Kuala Lumpur (HKL) and another from Selayang Hospital.

Dr Jeyaindran explains that increasing the number of teams would help make the process of transplantation more efficient.

He says the limited number of staff available to retrieve organs presents a challenge, especially when the deceased donor is located far away.

"Such teams have to go all the way there and the retrieval can be at odd hours.

"We want to double the number

The treatment involves the lining of the body's abdomen and a solution to clean the patient's blood.

"Peritoneal dialysis can be done in the comfort of a patient's own home. It is convenient and there is no need for patients to go to a hospital or dialysis centre like in hemodialysis treatments," he says.

In his Budget 2014 speech, Prime Minister Datuk Seri Najib Tun Razak had also announced the Government's initiative in promoting peritoneal dialysis by providing free Continuous Ambulatory Peritoneal Dialysis (CAPD) kits costing RM19,000 per unit.

The initiative benefited over 1,000 patients who can use the kit at home.

Pointing out that Malaysia has room for improvement when it comes to transplants, Malaysian

and overseas hospitals.

"But this number steadily dipped over the years and in 2014, only 81 transplants were recorded," says Dr Ghazali, who is a senior consultant nephrologist.

The dip is due to the overall drop in organ pledges, proliferation of dialysis centres and dwindling numbers of doctors qualified to carry out transplant procedures.

Dr Ghazali points out that Malaysia has a long way to go when it comes to organ pledges, compared to countries like Spain and Belgium.

In 2015, Spain recorded 39.7

actual deceased organ donors per one million population, compared to Malaysia which has about 0.6 per one million population.

Concurring that cases of CKD are on the rise, Malaysian Society of Nephrology council member Dr Lily Mushahar attributes the spike to the increase in elderly population in Malaysia.

"With better healthcare in Malaysia, the population now has a longer life expectancy. This leads to an increase in non-communicable diseases (NCDs) such as hypertension and diabetes that relate to long-term complications like

increase the capacity of medical staff to improve the level of transplants.

Calling it the ideal solution for kidney patients, he says transplants are also cheaper in the long run compared to dialysis.

"The main challenge when it comes to transplants is the need to increase the number of specialists, including transplant surgeons, pathologists and other supporting medical professionals.

"We are looking into roping in foreign and local experts to train more specialists in this area so that more transplants can be conducted and in a safe way too," he told *Sunday Star* recently.

Dr Jeyaindran points out that while only 1% of the Malaysian population had pledged their organs after death, it was still the "greatest gift" a person can offer.

"As such, we need to strengthen the mechanism to support such a gift of life to another in need," he adds.

of such areas so that they can reach more locations quickly and cover wider areas like Sabah and Sarawak," Dr Jeyaindran says.

Transplants can also be done involving living donors, who are often family members of the patient.

But for cases where the organ is from an unrelated deceased donor or cadaveric donor, there is also another hurdle – whether or not the organ is compatible with the patient.

"When the organ retrieval team gets an organ from Kuala Lumpur, it may not be suitable for a patient from the same place.

"But if it's a match for someone in Alor Setar, then the necessary logistics have to be done to deliver the organ and this could take time," he explains, adding that some organs may not last for long periods.

On dialysis treatment, Dr Jeyaindran says the ministry is focusing more on peritoneal dialysis, just like in Canada.

Society of Transplantation president Datuk Dr Ghazali Ahmad says the number of procedures done these days is a far cry from the past.

"In the 1990s, about 50 transplants were done in HKL itself.

"But last year, there were only 27 transplants from both living related donors and cadaveric donors in Malaysian public hospitals," he says.

And only two Malaysian public hospitals performed such procedures last year, namely HKL and Selayang Hospital.

Although private hospitals only perform transplants involving living related donors, he notes that the total number of overall transplants is low and has been declining between 2009 and 2014.

"In 2009, a total of 141 transplants were conducted involving Malaysian patients in private, public

## The organ transplant wait list



## Organ transplants for Malaysians


The number of organ transplants (from deceased organ donors and living related donors) has been declining since 2009.

The following shows the total number of transplants done in public and private hospitals in Malaysia as well as overseas for Malaysian patients.




## Kidney failure in Malaysia

For every **100 Malaysians, nine** have chronic kidney disease (CKD), ranging from stage one to five.




An average of **7,000 new cases of stage five CKD** were reported every year for the past three years.



Malaysia has the **7th highest** dialysis treatment rate in the world, behind Taiwan, Japan, Singapore, USA, Korea and Portugal.

However, it has one of the **lowest** organ donation rates in the world.

The total number of adult patients with CKD is estimated to be between **two and three million**.



A total of **381,353** people signed up as organ donors as of Jan 31, or about 1% of the Malaysian population.



As of last year, there were **20,988** on the organ transplant wait list, with over **90% being kidney patients.**

**60%** of end stage renal disease cases in Malaysia are caused by diabetes.



There are currently less than **10 transplant surgeons in Malaysia.**



Sources: Health Ministry, Malaysian Society of Transplantation, Malaysian Society of Nephrology, National Kidney Foundation Malaysia

kidney disease," she says.

As such, the rise in NCDs over the last two decades, especially diabetes and hypertension, has led to the corresponding hike in kidney failure.

"Sixty per cent of end stage renal disease in Malaysia is caused by diabetes. Unhealthy lifestyle and diet among Malaysians also give rise to obesity and NCDs," Dr Lily says.

Another factor is the lack of awareness among Malaysians, as many do not go for regular medical screening.

"They only do so when they become unwell and find out they have the disease," she laments.

While Malaysia has enough nephrologists – about 120 for the country's population of 30 million – Dr Lily finds it worrying that there are so few dedicated transplant surgeons.

"Most transplants are being done by general surgeons who are also involved in other daily duties.

"Malaysia needs a dedicated transplant team that comprises dedicated transplant surgeons, anaesthetists, nephrologists, nurses, psychiatrists and nutritionists that do not juggle their work with other non-transplant duties," she says.

The National Kidney Foundation is also doing its part to help kidney patients by developing centres in underserved areas, especially in East Malaysia, to provide treatment for poor patients.

"We are also introducing another programme to help those with early kidney disease from progressing to advanced kidney failure.

"We hope to kick off this pilot project this year," says its chairman Datuk Dr Zaki Morad.

## Take care of your kidneys



Two major contributors of CKD are diabetes and high blood pressure. **Conduct regular medical screenings** to keep your health in check.



**Eat a balanced diet.** Reduce salt, fat and sugar in your diet. Add more fibre, fresh fruits and vegetables.



**Quit smoking** because it can damage blood vessel walls. Damaged blood vessel walls can cause insufficient blood supply to organs including your kidneys.



**Avoid unnecessary medication** as some can be toxic to the kidneys if taken in large amounts over long periods. Seek advice from your doctor on what to avoid.



Maintain a healthy weight. **Exercise** for 30 minutes for at least three times a week.

## Carrying on beyond kidneys

SHE was pregnant when she found out that she had kidney failure.

To protect her, the doctor suggested that she terminate her pregnancy as it could be life-threatening.

But Junaidah Abdul Manap asked the doctor to save her baby and in the seventh month, the doctor performed a caesarean section and her daughter was born.

"I was devastated when I found out about my condition. But I am glad I managed to be a mother," says the 37-year-old Islamic studies teacher, whose daughter is now four years old.

While her condition does not allow her to have any more children, Junaidah is grateful that she was able to form a small but happy family.

"I now depend on peritoneal dialysis but I do hope to receive an organ transplant one day," says Junaidah, who conducts the dialysis three times a day at home.

Having relied on dialysis for the past four years, she says while she is unable to do certain activities like swimming, she carries on with her life as a normal person would and watches her diet strictly.

"Now that I have a child, I want to make sure I am healthy so I can take care of her.

"For those who are newly diagnosed with the disease, my advice is do not despair. If you do not have a positive mind, you won't be able to do anything. Just keep living," she says.

Another dialysis patient, known only as Lim, says she continues to be a happy-go-lucky person despite having kidney failure.

**For those who are newly diagnosed with the disease, my advice is do not despair. Just keep living.**

Teacher Junaidah Abdul Manap, 37, who has been on dialysis since 2013

**I don't want any of my relatives to go through what I'm going through.**

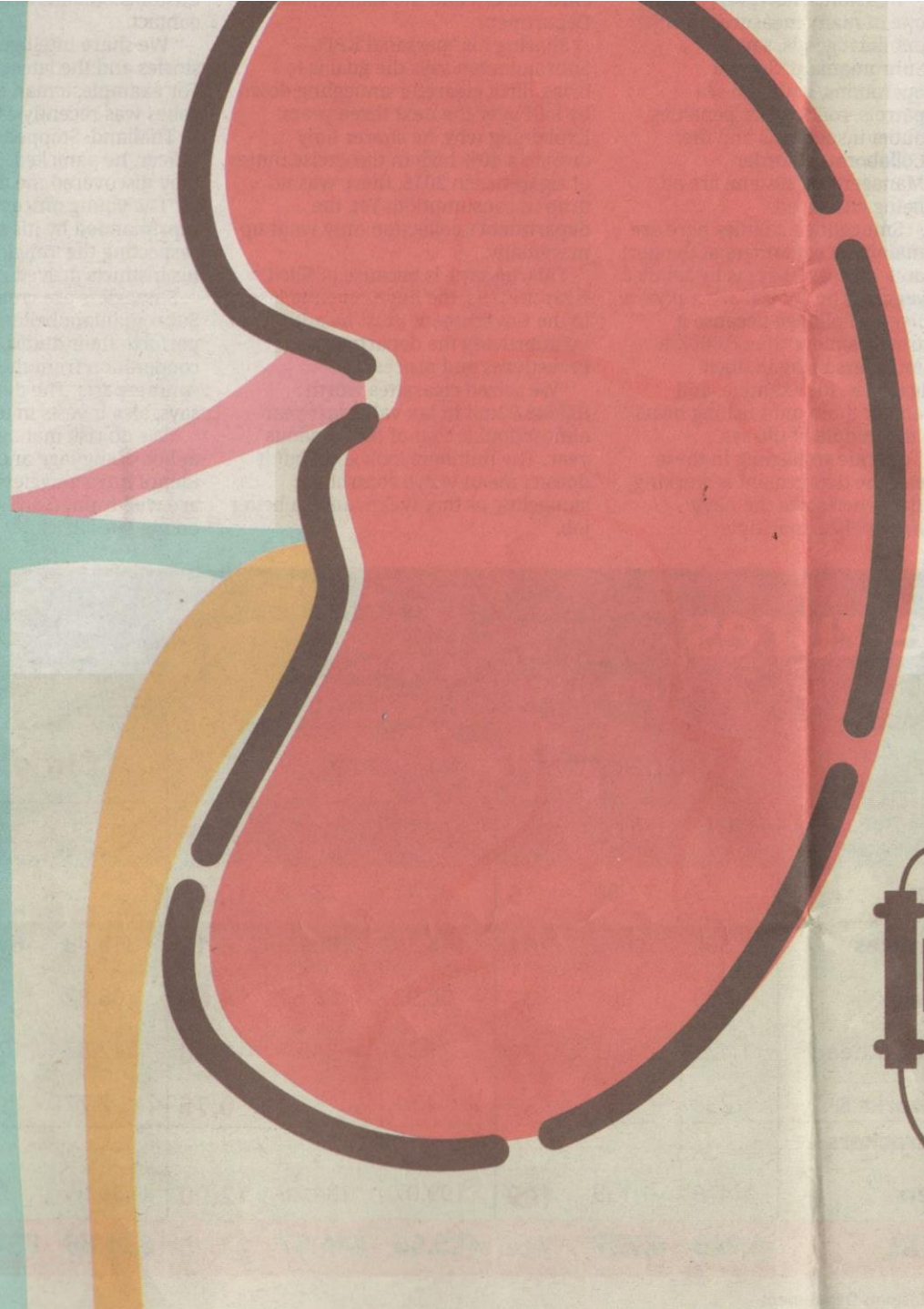
A dialysis patient known only as Lim, 52

Alex, says the rate of kidney disease in Malaysia is something that concerns him, especially since his family has a history of diabetes.

"I have yet to pledge my organs but I will do it soon.

"The more pledges we have, the better and brighter future for our children as their life expectancies will be longer with a better health-care system," says the 32-year-old IT consultant.

Malaysian Society of Nephrology council member Dr Lily Mushahar advises the public to go for regular health checks, as chronic kidney disease does not present any symptoms in early stages.



"I travel a lot and continue to run charity activities in my spare time," says the 52-year-old, who has been on dialysis for the past three years.

While her doctor encouraged her family members to be living organ donors to her, Lim says that is not what she wants.

"I don't want any of my relatives to go through what I'm going through.

"I am satisfied living on dialysis for the rest of my life," says Lim, a teacher from Seremban.

While she welcomes the Government's initiatives in increasing the number of transplant doctors, Lim says she has made dialysis a part of her life and is used to it.

"Patients should not blame anyone for their condition. And they also shouldn't view dialysis as something troublesome as it is an important treatment that helps us," she says.

A father of a six-year-old boy, who wishes to be known only as

in early stages.

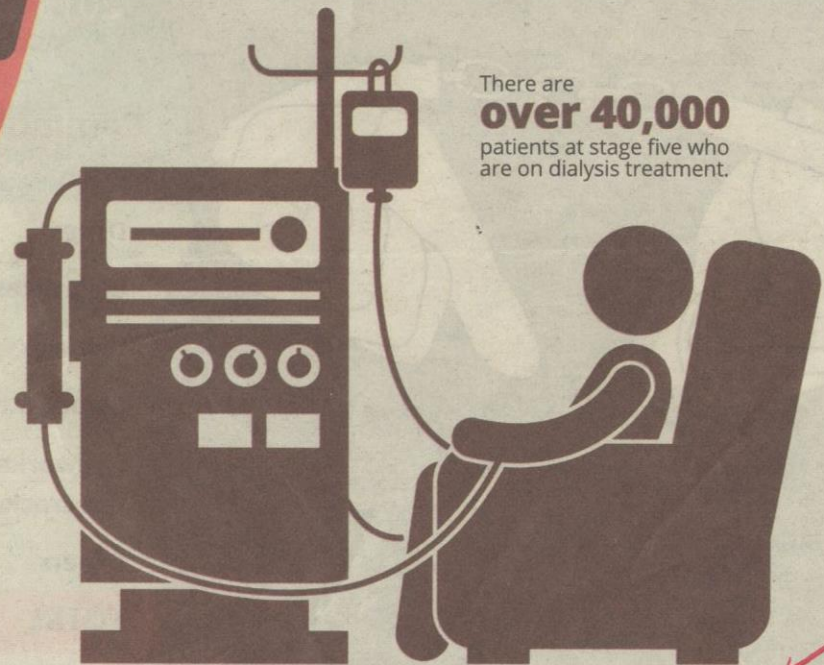
"This is especially important for those in the high-risk group such as Malaysians aged above 55, those with underlying diabetes or hypertension and those with a family history of kidney disease and renal stones," she says.

Dr Lily, who is a senior consultant nephrologist, also urges Malaysians to avoid buying alternative medication and over-the-counter drugs for kidney disease in local pharmacists.

"A lot of advertisements, including on social media, are available in the country promoting alternative medication.

"Such products have a potential side effect that goes unnoticed in early stages. It has a risk of worsening chronic diseases and could lead to organ damage such as kidneys and liver injury.

"This injury is potentially irreversible," she warns, adding that patients should seek their doctor's advice before purchasing any other medication.



There are **over 40,000** patients at stage five who are on dialysis treatment.