

Are you living with End Stage Kidney Disease?

Whether it's you, someone you know or you're storing the information for later, living with end stage kidney disease can be done – with the right guidance, mindset and willpower.

When you hear the words 'kidney failure', your thoughts immediately turn to the gloom – is there anything you can do to resolve this, how will you survive it, how will this impact the quality of your life, the list of concerns go on. Unfortunately, kidney disease is a long-term problem and it is not reversible. The good news is that with the proper information and guidance, you can still maintain the quality of your life, although there are lifestyle changes that need to be made.

NECESSARY TREATMENT

What is essential in managing end stage kidney disease? It is getting the right treatments, such as dialysis and medications. "Dialysis is a treatment that does some, but not all, of the

things that are normally done by healthy kidneys," says Dr Kong Wei Yen, Visiting Nephrologist at IMU Healthcare Dialysis Centre and Consultant Nephrologist at UKM Medical Centre. "It is not a choice when the doctors tell you that you need long-term dialysis. It is a necessary treatment so that you can stay alive when the kidneys fail. Dialysis treatment usually makes the patient feel better after a few months. It improves the quality and increases the longevity of life for the majority of patients."



Dr Kong Wei Yen

Patients with end stage kidney disease can opt for either one of the two types of dialysis – haemodialysis or peritoneal dialysis. “Kidneys – in layman terms – filter out the toxins and retain the necessary substances inside our body. However, when your kidneys fail, you will need artificial filters to clean out the toxins,” says Dr Kong.

Although long-term dialysis frequently improves the quality and increases the longevity of life for the majority of patients with end stage kidney disease, it is not guaranteed so. “When the kidneys fail, other organs might fail as well. When long-term dialysis is needed, many patients already have very serious health issues including diabetes, heart problems and so forth,” says Dr Kong.

Medication, therefore, plays a huge role too in management of the disease, especially for patients who have kidney disease due to diabetes. In Malaysia, one out of four patients with diabetes have kidney disease. In fact, six out of 10 patients who undergo dialysis are diabetic.

Unfortunately, many patients are misinformed about medication, says Dr Loh Vooi Lee, Consultant Endocrinologist, IMU Healthcare. “High glucose levels actually damage the blood vessels in the kidney itself and when that happens, it destroys the architecture of the whole kidney. In addition, there is also blood pressure that needs to be controlled as it affects the blood vessels in the kidney too. One of the important myths is that the medication we prescribe for this will damage the kidneys,” he says.



Dr Loh Vooi Lee

The truth instead? Medication actually protects the kidneys from further damage. “The dosage will be adjusted according to your condition but you must continue to take it at all times. It is not the cause of kidney disease but in fact, it is protective,” says Dr Loh. “That and healthy lifestyle habits – like quit smoking, limiting salt intake, exercise, a healthy weight and enough rest – are basic things you have to follow to keep the kidneys healthy.”



YOU ARE WHAT YOU EAT

When it comes to management of diseases, diet often plays a huge role. In the case of kidney disease, healthy eating takes on a special meaning, says Prof Winnie Chee Siew Swee, Department of Nutrition & Dietetics, International Medical University.

“Approximately 40 to 50 per cent of patients on dialysis are actually malnourished as the process of

dialysis breaks down your body proteins, making you lose the nutrients that you need. It is important to make sure that you maintain your nutrition status as the term healthy eating changes when you have kidney disease and is on dialysis,” says Prof Chee.

Many end stage kidney disease patients are told to cut down their protein intake as it accumulates waste product. This is true to a certain extent, says Prof Chee, but if you’re on dialysis, you actually need to do the opposite. “When they are diagnosed with kidney disease, patients are told to cut down their protein. So when they get onto their dialysis treatment, they are still afraid to eat protein when in fact they now need to increase their protein intake. This is because the dialysis process itself drives out the protein. The body breaks down the protein and gets dialysed out when you actually need it so you have to switch to a high protein diet,” says Prof Chee.

Other dietary precautions? Be careful of your selection of fruits and vegetables intake that may be high in potassium that can only be excreted from our kidneys. Also, many dialysis patients may sometimes experience constipation due to the limited amount of water they drink.

“We want patients to know that we are here to teach them how to enjoy their food in a safer manner that won’t give them problems,” says Prof Chee.



Dr Shane Varman

GETTING SUPPORT

When it comes to managing end stage kidney disease, the emotional and psychological state of mind makes a lot of difference. Sadly, individuals with kidney disease who are depressed rarely seek help as there is shame and stigma towards mental health treatment.

"Dialysis causes burden, from lifestyle restrictions to social isolation to the financial cost of it all. The individual's quality of life declines. Essentially, when one is diagnosed with end stage kidney disease, it is the notion of losing control over their lives that will make patients think about their existence and mortality. Some individuals contemplate dying. Being told that they now need to be dependent on machines and medication will have an adverse impact," says Dr Shane Varman, Consultant Psychiatrist, IMU Healthcare.

Depression and anxiety can easily set in. "This may prevent them from adapting to changes - such as complying with their medication regime or diet and leading a healthy lifestyle. Thankfully, in Malaysia, counsellors, psychologists and psychiatrists are available in most government and private hospitals to assist patients and caregivers - so they can continue to live fulfilling lives. The National Kidney Foundation (NKF) offers financial support and training courses. SOCSO offers financial support for dialysis. For civil servants and pensioners, the government pays for cost of dialysis. Various other religious bodies throughout Malaysia subsidise the cost of dialysis. However, primary prevention is still the best - controlling diabetes hypertension and obesity, and listening to your doctors' advice to prevent kidney disease," says Dr Varman.

"It is not the end of the world when you are diagnosed with end stage kidney disease. You can think of it as being given a second chance to live and stay healthy, relatively speaking. The rules are simple, says Dr Kong. "Just follow the instructions from the nurses, doctors and dietitians, and you might live a better and longer life."



Dr Benjamin Cheah

KIDNEY DISEASE IN LUPUS PATIENTS

SLE (Systemic Lupus Erythematosus) is an autoimmune condition where the body's immune system attacks the body itself. Every organ can be affected and one of the major commonly affected organs is the kidney.

"Between 40 to 70 per cent of lupus patients will have kidney issues. The immune system attacks the kidneys and causes damage to the filtration system," says Dr Benjamin Cheah Tien Eang, Consultant Physician and Rheumatologist at IMU Healthcare.

The biggest problem with treatment in this case is also patient adherence. "A lot of times patients do not follow up", says Dr Cheah. This, according to the doctor, is due to the fact that treatment for lupus will include steroids that has many side effects, among them is weight gain. This can be distressing to lupus patients.

"We are duty bound to inform patients of all the side effects of the treatments given. In contrast, a lot of alternative therapies may tell patients what they want to hear - no side effects, all natural and the potential for cure. Things that patients love to hear, albeit unsupported by scientific evidence," says Dr Cheah.

Another issue with lupus? The poor awareness of the disease, particularly in Malaysia. This may result in a delay in the diagnosis, which can lead to more serious organ damage and a poorer quality of life. It also results in patients feeling isolated and alone, and invites social stigma.



This article is courtesy of International Medical University and IMU Healthcare in a bid to spread greater awareness about chronic kidney disease.