The National Kidney Foundation of Malaysia (NKF) No. 70, Jalan 14/29, 46100 Petaling Jaya, Selangor. Tel: 03-7954 9048, Fax: 03-79577328 / 79540535, Email: info@nkf.org.my



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Editor's Message

he first issue of SHARE, the official newsletter of the NKF of Malaysia was launched in January 1996. The aim of the newsletter was to inform the public, patients, donors and well-wishers of NKF about kidney disease and other kidney-related issues and what the NKF is doing to make a difference,

Over the years SHARE has undergone several changes in format and contents, Ultimately however, the aim of the editorial team is to make the newsletter as readable as possible with features and articles which are informative and of interest to the readership,

This issue of SHARE again looks at issues related to the most severe form of kidney disease - severe kidney failure - its prevention and treatment, Ninety percent of patients requiring dialysis are on haemodialysis.

Ten percent however are on the other form of dialysis therapy known as Continuous Ambulatory Peritoneal Dialysis or CAPD in short, The interview with Dr. Zaki touches on some of the advantages of CAPD versus haemodialysis. Kidney transplantation for patients with end stage kidney disease has the best outcome.

However, the transplantation rate in Malaysia is dismal not because of lack of potential donors but because of lack of willing donors. The "Do You Know" series on the back cover looks at who can be an organ donor (almost everyone) and the supreme benefits to patients,

The families of patients particularly children with end stage kidney failure often times face seemingly insurmountable obstacles in trying to juggle between ensuring that the child on dialysis receives good care, yet at the same time the other children and the rest of the family are not neglected. This is more than exemplified by the article on "Coping with Kidney Failure - The Reality", a story about Tracy and Stephanie – a pair of 7 year old twins on dialysis whose family had to uproot themselves from Sarawak to Kuala Lumpur in order for them to receive dialysis treatment. There are many more stories of patients and their families who have in their own way become role models and heroes in their ability to rise above life's challenges.

Malaysia celebrates her 50th anniversary of Merdeka this year. She can be justifiably proud of the progress that has been made in ensuring that her citizens have adequate access to dialysis treatment. This is all thanks to the combined efforts of the rakyat, the politicians who have taken heed of the needs of the rakyat, the non-governmental organizations like NKF, and all the health professionals involved in the care of patients with kidney disease,

Syabas!

Dr. Lim Yam Ngo Chief Editor, SHARE

Directory of 20 NKF Dialysis Centres

 Tuanku Syed Putra - NKF Dialysis Centre, Kangar, Tel:04-9777411
Lions Club - NKF Dialysis Centre, Alor Star, Tel:04-7352190 • Superkids Trinity - NKF Dialysis Centre, Alor Star, Tel:04-7340215 • FoYi - NKF Dialysis Centre (Unit 1), Penang, Tel:04-2824952 • FoYi - NKF Dialysis Centre (Unit 2), Penang, Tel:04-2825367 · Moral Uplifting Society - NKF Dialysis Centre, Ipoh, Tel:05-3215921 • Moral Uplifting Society - NKF Dialysis Centre, Taiping, Tel:05-8041633 • NKF Dialysis Centre Jalan Hang Lekiu, Kuala Lumpur, Tel:03-20312437 • Rotary Club of Damansara -NKF Dialysis Centre, Kepong, Tel:03-62517460 • Nanyang - NKF Dialysis Centre, Setapak, Tel:03-40217704 • Charis - NKF Dialysis Centre, Cheras, Tel:03-91328193 • NKF Dialysis Centre, Petaling Jaya, Tel:03-79542359 • Ping Rong - NKF Dialysis Centre, Petaling Jaya, Tel:03-78802103 • Bakti - NKF Dialysis Centre, Klang, Tel:03-33239424 • Apex Club - NKF Dialysis Centre, Klang, Tel:03-33418009 • Che Luan Khor - NKF Dialysis Centre, Kluang, Tel:07-7765313 • Family Development Foundation - NKF Dialysis Centre, Johor Bahru, Tel:07-3866164 • NKF Dialysis Centre, Kota Bharu, Tel:09-7475834 • Terengganu - NKF Dialysis Centre, K, Terengganu, Tel:09-6249423 • KAS/Rotary - NKF Dialysis Centre, Kuching, Tel:082-240927

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Coping with Kidney Failure - The Reality

Interview with a mother of twins currently undergoing treatment at HKL





Serina showing the site where the catheter was inserted for the dialysis

The twins seeking treatment at Hospital Kuala Lumpur.

here are many parents, family members and caregivers who faced with the harsh reality of end stage kidney disease cannot come to terms with the onset of kidney failure being faced by their loved ones. For the dialysis patient himself the shock of being diagnosed with end stage kidney failure can have a drastic impact on his home and working life, Many have to make lifestyle changes and adapt to a different way of life with greater dependency on their loved ones,

For the family members, they too have to adapt to changing circumstances and depending on what type of dialysis is chosen, they have to be emotionally supportive of the dialysis patient.

There are many patients who cope by attending counselling sessions, where they are advised that kidney failure does not mean the end of life, Instead, with proper treatment, it represents a second chance at life and many go on to lead normal lives with love and support from their families.

However, when faced with dialysis and the initial shock of seeing their loved ones, especially children being dialysed may prove too painful and many choose to hand over the reins to close family members till they are emotionally ready to take on the added responsibility.

Some choose to take a more positive attitude and the beneficiaries are the family members who with care and support go on to lead normal lives. Parents strive to do the best for their children at great cost emotionally and many feel the stress of the changed lifestyle, making allowances both financially and otherwise to cope,

When Stephanie Thomas, 7 years, fainted in October 2006, her mother never imagined her daughter, one of a set of twin girls, was suffering from end stage kidney failure. Her mother, overcome with worry, was told by the local clinic that her daughter would need to be transferred to Miri Hospital and it was there the mother faced the heartbreaking news, both her daughter's kidneys had failed and Stephanie would need to be dialysed immediately or her life would be in danger,

According to her mother, Serina anak Merang, 26 years, both girls were born healthy and were always happily playing together with their brother at their home in Miri, Sarawak, The father, Thomas Tijun, worked in the oilfields in Bintulu and there was no indication of any health problems with the twins when they were young.

When Stephanie fell ill and had to be dialysed, her parents immediately sent Tracy for a check-up, only to discover that she too was facing problems and the doctor advised dialysis for Tracy as her blood had traces of urea and waste which could lead to long term complications if not dialysed, Thus, as Serina realized she had to cope with two young children on dialysis and it did take a toll on her and her family. For Tracy and Stephanie to receive dialysis, she had to move to the Klang Valley with all her children while the father had to continue working in Bintulu, Her whole world was turned upside down and she was literally living for the twin girls to get better and for a few months, they were the source of all her attention.

Today, while Stephanie and Tracy are both on Continuous Ambulatory Peritoneal Dialysis (CAPD), Serina, having undergone training under renal (trained) trained nurses, at the Paediatric Institute, Hospital Kuala Lumpur, "I am grateful that both of them are well-looked after today," said Serina,

She also feels lucky as the Social Services Department realising the dire need for expert medical attention paid for her trip to Kuala Lumpur, where today both Tracy and Stephanie receive expert medical attention from the Paediatric Institute, attended to by Paediatric Nephrologists.

Being away from home has been a sad experience for the whole family but with supportive relatives in Shah Alam, where Serina currently resides, has strengthened her resolve to do the best for the twin girls, "One day, we will all return to Miri and be together as a family and by that time the twins will be ready to attend school," said Serina, with a smile on her face.

The 5th NKF Patient Forum

The Role, Financial Assistance & Job Opportunities of Agencies for End Stage Kidney Failure Patients.

As part of its ongoing efforts to educate dialysis patients on the various means of obtaining information on patient subsidy and financial assistance for dialysis as well as employment opportunities for those currently undergoing dialysis, the National Kidney Foundation of Malaysia organised a Patient Forum on the Role, Financial Assistance and Job Opportunities offered by Government and Non-Government Agencies for End Stage Kidney Failure Patients, which was held recently in one of the hotels in Petaling Jaya. Many patients accompanied by their family members from all over Klang Valley signed up for the Patient Forum as they were especially interested in the financial assistance provided by the various government agencies and the pension paid to those who are eligible due to end stage kidney disease.

Various speakers from the Ministry of Health, Social Security Organisation (SOSCO) The National Welfare Foundation, The Social Welfare Department touched on the various allowances given out for those suffering from kidney disease and in the case of the Social Security Organisation, the 'pension ilat' or invalidity pension which is made available to those who are unable to work due to the illness. In his speech, Goh Seng Chuan, Chief Executive Officer, National Kidney Foundation of Malaysia (NKF) said NKF is aware of the crucial role played by government agencies in providing financial assistance to those who cannot afford to pay for the high cost of dialysis and these agencies have been invited today under one roof to give a talk as well as provide an opportunity for dialysis patients to be informed and understand the various financial schemes that are available to help dialysis patients reduce their financial burden and that of their families.

At the Forum, many patients came forward to clarify many issues related to the financial assistance they received and some who were working were advised not to stop working and to apply for the pension if they are eligible for it.

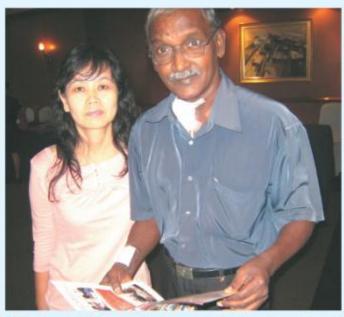
Leela Ramadas, Senior Assistant Secretary, Ministry of Health (MOH), explained that her area of work was specifically the RM50 subsidy given out to NGOs by MOH for dialysis patients and in the case of non-governmental organizations (NGOs), they carried out the initial screening of those applying for the subsidy and the socio-economic report was then sent to the MOH for final approval. The Ministry of Health had ensured only those in need would qualify and certain guidelines were in place to ensure only the poor and the needy would be entitled. Leela also said the MOH had an audit and investigation committee for the purposes of carrying out checks on newly set up NGO dialysis centres before the subsidy was disbursed to them.



The registration of participants for the 5th NKF Patient Forum 2007



Amarjeet Singh raising a question to the SOSCO officer, Dr. Ahmad Kamal with regard to the RM500 grant for dialysis patients



Lourdes with wife Peggy at the Forum, gathering information on financial assistance made available by government agencies

Before the tea break dialysis patients were shown the NKF produced video, 'Getting Started', depicting the stages a dialysis patient goes through before haemodialysis and the steps that needed to be taken. Another interesting video viewed by dialysis patients, 'Bone Metabolism in Kidney Failure Patients' emphasized the importance of maintaining bone density while undergoing dialysis.

Another speaker, Aida bte Abdul Jalil, Executive Officer, Legal and Advisory Unit, The National Welfare Foundation said the biggest problem was the lack of completeness in many of the documents submitted by those applying for financial assistance and other forms of aid and time was wasted in contacting the parties concerned and then re-submitting for approval. As a foundation, YKN has to work towards raising funds for the benefit of the more than 821 dialysis patients under their umbrella who received RM4,219,820 for their dialysis treatment disbursed to more than 96 dialysis centres in 2006.



Dr. Tan Chwee Choon presenting a token of appreciation to Norhafizah bte Ahmad, one of the speakers from The Social Welfare Department



Md Hatta, The Human Resource Department presenting a hamper to one of the lucky winners

Lourdes Edward together with his wife Peggy Chia, said this was their first Patient Forum they had attended, Lourdes, a Project Coordinator had been recently diagnosed with End Stage Kidney Failure in July this year and was currently being dialysed at the Berjaya-NKF Dialysis Centre, "I found the forum very useful as being recently diagnosed with End Stage Kidney Failure, I was unaware of the financial assistance being offered by the various government agencies and the many schemes available as money is an important consideration in the long term as I have three children to maintain and support," said Lourdes,

Another question raised by patients in connection with the RM500 grant to be given out by SOSCO annually for dialysis patients under the Budget 2007 to Dr. Ahmad Kamal bin Mohamad Nor, SOSCO officer at the forum, was to confirm whether it is for the benefit of all dialysis patients whereby the amount would be paid directly into the accounts of dialysis patients or the centre concerned, Dr. Ahmad Kamal said once the details and centres had been worked out dialysis patients would have the amount paid into their individual accounts at the centre concerned.

Dialysis patients were also encouraged to work productively and contribute positively to their employers and Assistant Director Md Hatta bin Md Jauhar from The Human Resource Department cited many cases where companies were so impressed with the productivity of their employees that they actually purchased dialysis machines to be used for the employees at the company's premises, He advised all the dialysis patients present to continue working and if they did to have a cheerful disposition and one that would motivate their employers to want them at the workplace,

Dr, S,S, Gill, Chairman of the Board of Managers, NKF said in his speech the government should one day consider giving dialysis free in Malaysia as is done in countries such as America where the burden of dialysis was borne by the government, However, since this was not yet available to dialysis patients here, those who could work were encouraged to do so to lessen their financial burden if they did not qualify for financial assistance from government agencies,

The Forum ended with a Q&A session where dialysis patients were given the opportunity to raise questions to the panel of speakers comprised of those who had earlier presented their various papers from organizations such as SOSCO, The Human Resource Department, The Ministry of Health and representatives from the National Kidney Foundation,

All dialysis patients participated in the NKF Survey at the Forum and eight were the lucky winners of hampers. Many also visited the exhibition put up by the Public Education & Communications Department, NKF to view the many posters on the early detection and prevention of kidney disease,

The overall response with more than 300 dialysis patients in attendance showed there were many interested in the topic presented at the Forum and judging from the many questions, the Forum had provided a window of opportunity for patients to have their questions and problems on financial assistance answered.

PERITONEAL DIALYSIS -**A TREATMENT**

While many associate dialysis with being hooked up to a machine for 3-4 hours, there is an alternative which is more convenient and allows the patient to be more in control. Not so well-known, of the 15,000 dialysis patients in Malaysia, only 1,300 to 1,500 are on peritoneal dialysis (PD), a process in which the patient has a catheter permanently inserted in the abdomen, connected to fluid bags.

For many it is a lifestyle choice, some want to be able to lead a normal life without being dependant on a haemodialysis machine, others want to travel and prefer to carry the fluid bags to a hotel room, connect the catheter in their abdomen to the fluid bags for about half an hour, 'clean' out the waste products that the damaged kidneys are unable to filter. This would be done four times a day, some even boast of being able to 'wash' their kidneys on top of mountains, while trekking in the Himalayas, indeed a far cry from being hooked to a machine for 4 hours.



Patients on haemodialysis have to be present at the dialysis centre thrice weekly to be dialysed.

Haji Mohd, Abas, 66 has chosen PD as it allows him to be in his house, daily, playing with his grandchildren, who he cares for with his wife, "I have a room specially set up in my house and it is cleaned and mopped everyday by my wife, who is meticulous about the cleanliness issue as we are aware that this form of dialysis can lead to infections and we take greater care," said Abas,



Abas enjoys the freedom offered by PD and is happy working in his garden



Currently Abas on CAPD at home, finds he can have quality time with his

According to Consultant Nephrologist, Dato' Dr. Zaki Morad Mohd Zaher, Vice-Chairman, Board of Managers, National Kidney Foundation of Malaysia, in 1984, there were only 12 patients in the entire country on PD and it was only available in Hospital Kuala Lumpur.

Today there are about 22 centres for PD, 18 of which are under the Ministry of Health. Still, Dr. Zaki commented there is a vast disparity between the two forms of dialysis and he attributes this to the history of dialysis in Malaysia.

"We started 100% on haemodialysis, so far as the public is concerned, when you mention 'dialysis', they imagine haemodialysis. But today, there is a much greater understanding of peritoneal dialysis and there is a push for peritoneal dialysis where it suits patients who choose convenience and are willing to set up a room specially for PD," said Dr. Zaki.

Although cost effectiveness is the often talked about difference, according to Dr. Zaki, the costs of both haemodialysis and PD is the same. He said the big difference between the two forms of dialysis is that "patients on peritoneal dialysis have a better quality of life compared to patients on haemodialysis".

OPTION

Peritoneal Dialysis - The Process

There is a hollow space in our abdomen, where the abdominal organs like the liver, stomach and intestines lie. This space, sometimes known as the peritoneal cavity, is lined by a thin peritoneal membrane. This peritoneal membrane, filled with blood capillaries, where small pores allow the waste products to pass through, will bring waste products like urea, creatinine, sodium and potassium, to the peritoneal cavity. Water would also be removed in this process.

In peritoneal dialysis, a dialysis fluid is infused into the peritoneal cavity. The waste products and excess water move across the peritoneal membrane into the dialysis solution, which is then drained out into a drainage bag. "The exchange of PD fluids has to take place about three to five times a day. Each time about 2 litres of fluids are being infused into the body," said Dr. Zaki.

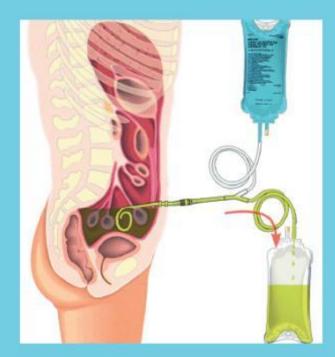
The continuous form of PD, called Continuous Ambulatory Peritoneal Dialysis or CAPD, has proved suitable for those with school-going children and those who hold full-time jobs. When Madam Chong (not her real name), 35, discovered she had end stage kidney disease, she chose PD as she had school-going children and could not afford to be missing 3-4 hours a day, 3 times a week.

"It was difficult as I had to continue working to support my children, one of whom was still in primary school and the other two in secondary school. I baked cakes and buns and sold them in the local pasar malam every night and the next day woke up early to send the children to school," shared Madam Chan.

Thus, the biggest beneficiaries of PD are children and young working adults because they do not have to take time out from school or employment to go for dialysis. The other advantage said Dr. Zaki was the fact that the patient need not have a fistula inserted or have the discomfort of needle pricks for each dialysis.

Peritoneal Dialysis - The Scenario Today

The perception has changed of PD, said Dr. Zaki, "When PD was first introduced 30 years ago, it was considered second-rate treatment as the technology was quite backward at that time. Today, the technology has improved dramatically and the major breakthrough has been in reducing one of the most severe complications, which is infection of the peritoneal membrane, or peritonitis. Patients just have to keep their catheter site and tubing clean and free from contact with bacteria."



The process of CAPD, showing the waste solution being drained out from the peritoneal cavity into the empty drainage bag, which is placed below the level of the abdomen.

However, the wise move that everyone knows but have not been following is the prevention of kidney failure. For Dr. Zaki, who has spent more than 30 years in the field of nephrology, kidney failure is not inevitable. If you take stringent measures like early detection and aggressive treatment of kidney disease, diabetes and high blood pressure, you can delay or even halt the progression of kidney disease.

Peritoneal Dialysis

Advantages

- Flexibility ability to fix time and place of dialysis.
- · There is continuous removal of waste products and excess water.
- · There is no use of needles,
- There are fewer restrictions on food and water intake.
- · Continuous therapy works better and resembles kidney function,
- Mobility- easy to set for the daily exchanges,

Disadvantages

- There is a need for storage place for the dialysis supplies.
- A room has to be allocated and kept clean for the dialysis.
- · A permanent catheter needs to be inserted.
- · If room not kept clean, there is a risk of infection,

NKF MOBILE HEALTH SCREENING

When Salmah Binti Hassan* discovered her urine was cloudy and seemed to be foamy, she told her husband but as they lived in a kampung in Sabak Bernam, serviced by a bus that regularly broke down, they were at a loss. Finally, they managed to hitch a ride with a neighbour to the clinic about fifteen miles away and were attended to by a doctor. For Salmah, she was concerned enough to make the trip to the local clinic but many Malaysians living in outlying areas would find it troublesome, only to face end stage kidney disease when both kidneys failed. Thus, those who live in the outlying areas of big cities and towns, healthcare is a luxury and many are unable to afford the cost of simple blood and urine tests.

Today, however, the National Kidney Foundation of Malaysia has planned for a kidney care outreach programme which may provide hope to residents living in out of town areas, who may be able to have simple blood and urine tests done on a mobile health screening unit. Goh Seng Chuan, CEO NKF feels it is timely as kidney disease is on the rise and early detection and prevention is the key to overcoming the high numbers of those on dialysis, the figure now stands at 15,000 Malaysians on dialysis with some of the dialysis patients being subsidized by the government. This involves a heavy financial burden on the government. The NKF Mobile Health Screening initiative, part of NKF's kidney care outreach programme for early detection and prevention of kidney diseases would bring health screening directly to the Malaysian public. The NKF Mobile Health Screening is able to provide massive, basic screenings that help to identify individuals who are at risk of getting kidney disease. The objectives of the NKF Mobile Health Screening are as follows:

- To offer the community easy accessibility to health screenings related to kidney diseases for early detection and prevention of kidney diseases.
- To provide referral for more comprehensive tests and/or treatment to individuals who have some form of kidney abnormalities, diabetes or high blood pressure.
- To provide counselling to high risk individuals to take precautions to adopt healthy lifestyle and diet.
- To increase awareness of the seriousness of Chronic Kidney Disease, its signs and symptoms, risk factors, and the ways to prevent it.
- To impart educational messages via video and educational pamplets on the prevention and management of kidney diseases.

The NKF Mobile Health Screening, the first of its kind in Malaysia by having a 40-seater bus conducting health screening and counselling on the bus. This is made possible by the generous sponsorship by The Sunway Group, which has helped to raise the funds from The Spirit of Care & Love Charity Dinner on 4th November 2006.

There will be seven work stations with tables and chairs in the mobile screening unit, 1 work station for urinalysis/ urine tests, 1 work station for random blood glucose and random blood total cholesterol, 1 work station for body mass index and waist circumference, 3 work stations for blood pressure and counselling and 1 work station for registration. 4 rows of double-seater reclining seats will be available as waiting area for the public. Educational video will be screened for the public to watch while waiting for the screening or counselling.

Health screenings offered are blood pressure, random blood glucose, random blood total cholesterol, urinalysis on protein, blood & glucose, body mass index and waist circumference. This is because the high risk group of Chronic Kidney Disease includes patients with diabetes, high blood pressure, public who are obese etc. Since the cost of the screening is rather expensive, to make the public appreciate the service provided by NKF, a nominal fee of RM2.00 will be charged for the health screening.

The Mobile Health Screening will be staffed by qualified nurses, health science graduate and health service assistants to provide counselling and health screenings. The pool of counselling staff will be able to provide counselling in Bahasa Malaysia, English and Mandarin or major dialects.

For this very first unit of NKF Mobile Health Screening, NKF will cover mainly urban and suburban areas. NKF is targeting at high traffic areas such as petrol stations, shopping malls, hypermarkets, supermarkets, colleges/ universities, religious institutions, office buildings and factories etc. to conduct the health screening. We welcome all these organizations to approach NKF to conduct such health screenings around their premises as part of their employees' benefits as healthy employees are definitely more productive and able to contribute more to the employers.

NKF is looking forward to launch the NKF Mobile Health Screening in mid December 2007 and this will be a major milestone in NKF history as part of our efforts to achieve NKF's mission of saving lives through preventive education and early detection of kidney disease.

The target audience for NKF Mobile Health Screening will be the general public of 18 years and above, especially the high risk groups for Chronic Kidney Disease, i.e. one who is or who has the following risk factors:

- · diabetes · high blood pressure · a family history of kidney disease, diabetes, high blood pressure · kidney stones · obesity
- above 50 years old diseases such as Lupus (SLE), Rheumatoid Arthritis etc on long term pain killers

^{*} not her real name

馬來西亞腎臟基金會(NKF)流動保健檢測

當莎瑪*發現她的尿液混濁,有泡沫時,她告訴了她 的丈夫。但是,他們居住在沙白安南(Sabak Bernam) 的一個鄉村,提供交通服務的公共巴士又經常發生故 障,令他們非常的惶恐不安。最後,他們搭乘鄰居的 便車到大約十五英哩外的診所看醫牛。

莎瑪為了自己的健康,顧意到當地的診所求診,但有 許多居住在遠離市中心的馬來西亞居民會覺得很麻煩 , 往往等到兩個腎臟都失去功能時,只能無奈的面對腎 衰竭。對於那些居住在遠離市中心的人,醫療保健是 奢侈的,有很多人甚至負擔不起簡單的血液和尿液檢 測的費用。

今天,NKF已計畫了一項首要外展項目,它提供居住在 市區外的居民,在一個流動保健檢測單位上做簡單的 血液和尿液檢測。NKF首席執行員吳聖全先生表示,流 動保健檢測的推出是適時的。腎臟病的數據在不斷的 增加,克服居高不下的透析治療數目的首要措施是及 早檢測和預防,政府也為一萬五千名透析治療的部份 病人提供津貼,承受沉重的負擔。NKF流動保健檢測 的創始,是NKF的關懷腎臟外展項目之一,是為及早 檢測和腎臟病的預防,把健康檢查直接帶給馬來西亞 的公眾。

NKF流動保健檢測能夠提供大量基本的檢測,幫助確 認那些有腎臟病風險的個人。NKF流動保健檢測的宗 旨如下:

- 為社區提供有關腎臟病的健康檢查,及早檢測和預 防腎臟病。
- 為有不正常的腎臟問題、糖尿病或高血壓的個人提 供建議以做更全面的檢測或治療。
- 為有高風險者提供個人輔導以採取防備措施,採納 健康的生活方式和飲食。
- 提高公眾對慢性腎臟病的醒覺,知道其症狀、風險 因素和預防的方法。
- 通過錄影帶和教育小冊子以教育公眾有關腎臟病的 預防和控制。

NKF流動保健檢測是第一個在馬來西亞利用四十個座 位的巴士,在巴士上提供健康檢查和輔導的一個流動 單位。這是在雙威集團 (The Sunway Group) 於2006年 11月4日鼎力支持所舉辦的關愛慈善晚宴所籌得的款 項贊助的。巴士上將有七個具有桌椅設施的工作站:一 個作尿液檢測的工作站·一個作血糖和血液膽固醇檢 測的工作站,一個測身高體重指數和腰圍的工作站, 三個測血壓和提供輔導的工作站,和一個進行註冊的 工作 站。另有四排雙座位子作為公眾等候區域。在等 待檢測和輔導時,公眾可觀賞教育錄影片。NKF流動保 健檢測提供的健康檢查包括血壓、血糖、血液膽固醇 、尿液中的蛋白質、血液和葡萄糖、身高體重指數和腰 圍。這是因為慢性腎臟病的高風險群包括糖尿病患、 高血壓病患和肥胖症者等。NKF流動保健檢測提供的 健康檢查的費用是相當昂貴的,為了使公眾重視由 NKF所提供的服務,我們將會象徵性的每人收費二 零吉。

NKF流動保健檢測將由合格的護士、保健科學專業人 士和保健服務助理提供健康檢查和輔導。輔導員將會 以國語、英語、華語或主要方言進行輔導。

作為NKF的第一個流動保健檢測單位,它覆蓋的區 域主要是都市和郊區。NKF將針對人潮多的地點例如 加油站、商場、大型超級市場、超級市場、大專院校 、宗教機關、辦公樓和工廠等提供健康檢查服務。我 們也歡迎這些機構來響應這項計畫,接洽NKF,在他 們的 辦公室或辦事单位推动健康檢查,将它纳入員 工福利計畫;因為健康的雇員必定具生產力,能对雇 主更多的貢獻。

NKF希望在2007年12月中旬推出NKF流動保健檢測, 這將是NKF達成預防教育和及早檢測腎臟病以拯救生 命的使命的部份努力,它將是NKF歷史上的一個主要 的里程碑。

* 不是真實姓名

NKF流動保健檢測的主要目標是18歲以上的公眾,特 別是慢性腎臟病的高風險群,即有以下風險因素的人 +:

- 糖尿病
- 高血壓
- 有腎臟病、糖尿病、高血壓的家族歷史
- 腎結石
- 肥胖症
- 50歲以上
- 患狼瘡 (SLE)、風濕性關節炎等疾病
- 長期服用止痛藥

ADAY IN THE LIFE OF A



Albert Gunaratnam, 59 years, formerly a logistics manager from Shah Alam, has a lot in life to look forward to, a heart transplant patient in his 10th year with a donor heart, Albert treasures his time with his family and friends.

"I was put on the Institut Jantung Negara (IJN) waiting list for a few months and after a state athlete died in his twenties, I was one of the fortunate ones to receive a heart transplant in April 1998," said Albert from the comfort of his home in Shah Alam,

Unfortunately the same could not be said for the 4 patients still on the IJN waiting list for heart transplants.* Maswi Jaya Sukarmin, 47, from Kuantan died in August this year while waiting for a donor with a suitable heart as he was suffering from end-stage heart valvular disease.

Thus, Albert is among the few who succeeded when others failed.

Today Albert spends time with his wife, Terry Nelson and two daughters, and is a regular church-goer, travelling via the KTM Komuter to Brickfields every Sunday to attend church while helping out in the church choir.

During the period Albert waited for a heart donor, his wife Terry gave up her job and concentrated on helping Albert as he was weak and unable to perform even the simplest job chores. Today Albert looks back and feels family support is crucial during these times and even though his children were both facing exams, they gave their full support and understanding to him and today both are well-settled in their careers.

This year, there has been no heart transplant due to lack of suitable donors at Institut Jantung Negara (IJN)* and the situation has proved disheartening for all those waiting for organs especially in the light of the fact that the number of donors have gone up from 2,600 before 1996 to 107,048 today.

Sister Noorsalina Othman, Transplant Coordinator, IJN said Tee Hui Wi, 14 had been on a heart machine for a year, waiting anxiously for a heart donor and on the 29th September 2007, it would be exactly one year since Tee had been on the waiting list.

A member of the Green Ribbon Support Association, which publishing a from newsletter, organizes co-ordinates activities for those 'transplantees', the most famous being the Transplant Games, Albert lends his support and

comes forward for publicity campaigns as he believes public awareness is important for heart donors to come forward.

As the lucky recipient of a donor heart, Albert said he never takes his life for granted but instead gives thanks to God for the extra years he now has with his family and friends and hopes other donors in need and on the waiting list would be as fortunate as he was then,

gan Donation



TRANSPLANT PATIENT



Norasiken feels she has a happy home and a pleasant work environment at Hospital Kuala Lumpur

Norasiken Lajis alias Aziz, 45 years, is a bundle of energy and every now and then she laughs with her colleagues at work at the Post Graduate Renal Society of Malaysia located at Hospital Kuala Lumpur (HKL). Norasiken does not like to think of herself as a kidney transplant patient, instead she chooses to look on the bright side of life and feels she has much to contribute in terms of her time and skills to the community.

What is organ donation?

It is the gift of body parts after death for the purpose of transplantation. Transplantation is an operation which involves the replacement of diseased and defective organs and tissues with healthy organs from donors.

This treatment helps saves lives as those who receive the organs might die while on the waiting list for organs.

How can I become a donor?

Complete the donor pledge form and the donor card. The form can be obtained from the National Kidney Foundation or the National Transplant Resource Centre. Forward the form to the National Transplant Resource Centre (ntrc@hkl.gov.my) or to the National Kidney Foundation (edu@nkf.org.my) and keep the donor card in your wallet or handbag at all times. Please inform your family of your wish to be an organ and tissue donor after your death.

Having undergone the transplant in 1999, Norasiken was on peritoneal dialysis for 9 years previous to the transplant and it came as a welcome relief as she was then able to lead a normal life and today she is an active community volunteer.

At the time of the interview, Norasiken was busy preparing the Persatuan Anak-Anak Merdeka for the Merdeka celebrations and having herself being born on Merdeka Day, she was looking forward to the 50th year celebrations. During her spare time Norasiken confessed to being an active participant in Quran reading competitions and also a member of the Persatuan Kompang EZHAR, training young children in the use of the 'kompang', of which her uncle was head of the

With such an active lifestyle, Norasiken felt that even though she had no children of her own, all her nieces and the children living in the surrounding areas near her house in Selayang Baru constituted her family and were close to her. Having married at the age of 19 and had two miscarriages as a result of high blood pressure that she was unaware of, Norasiken wants to reach out to as many children as possible.

"The children today are bored and with their parents working they need to be engaged in activities which will benefit them and the community and since I enjoy teaching and guiding the children I hope to continue training them," said Norasiken.

Norasiken said prior to her transplant, when she was warded into Hospital Kuala Lumpur for a year, the consultant nephrologists in charge of her case gave her emotional and psychological support and as a result she felt ready to face the problems associated with end stage kidney failure and finally when she had the transplant, she felt she had achieved some quality of living in her life.

Even after she had the transplant, Norasiken was taken under the wing of Hospital Kuala Lumpur and offered a job as a clerk. "I felt very supported by the nephrologists and the staff who gave me the motivation to do something with my life and not feel sorry for myself," said Norasiken.

Today Norasiken hopes other end stage kidney failure patients would have the same access to a kidney transplant that she had. Unfortunately, statistics by the National Transplant Resource Centre show that 13 kidneys were received in 2006 while this year up to 31st August 2007, 12 kidneys have been donated so far for transplants, National Kidney Foundation Vice-President Dato' Dr. Zaki Morad Mohd Zaher said that a lot of lives could be saved if the body organs of at least 10% of the 6,000 deaths that occur annually due to road accidents could be used for kidney transplants.



IMPACT OF CHRONIC ILLNESS ON

By Dr. Sivakumar Thurairajasingam, Psychiatrist, Permai Psychiatric Institution, Johor Bahru

Chronic illnesses have become the leading cause of death in industrialized societies in the twentieth century with the major developments in health services. Chronic illnesses already account for 72% of the total global burden of disease in people over 30 and is postulated to increase by 17%, mainly in developing countries. Due to the chronic course they run, they present as long-term stressors, out of which 20-25% of patients have some form of psychological disturbance. These growing populations of patients survive acute critical illness only to become "chronically critically ill".

Psychological adjustment to chronic illness is a changing process, moving from initial 'shock' and 'denial' to a gradual acceptance and adjustment to the new disease state. Individuals react very differently within this process but similar to the stages of a normal grief reaction (Table 1). In a chronic physical illness, the focus of concern is the interaction of a disease with an individual, the family, or a system named the bio-psycho-social system (Engel, 1980). The system basically describes the interaction between the biology (functioning of the body system), psychology (functioning of the brain system) and social (behavioural functioning) of the human body.

Table 1. Phases of reaction to chronic disease (Bowlby, 1961)

Phase I	Shock & protest	Encompasses numbness and acute dysphoria
Phase II	Preoccupation	Encompasses yearning, searching and intrusive thoughts
Phase III	Disorganization	Disease is reluctantly accepted
Phase IV	Resolution	Inappropriate attitudes are rejected and acceptance to disease

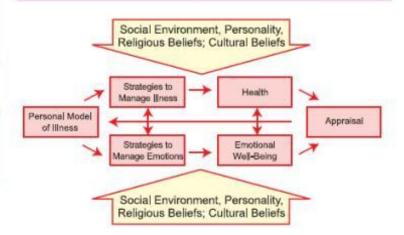
Behaviour influencing health can be classified in positive and negative terms as "health protective" or "health-risk" behaviours. Chronic stress is one example of how behavioural pattern can give rise to adverse psychological changes leading to the onset of an illness. In chronic stress these problems are developed through direct and indirect effects caused by hormonal changes in the brain which increases the levels of steroids in the body. This change slows down the process of wound healing and increase susceptibility to infectious disease.

Health behaviour, according to the "social cognition model" also states that it can be regulated by the person's beliefs about a particular health issue, the acceptance of symptoms and the understanding of illness. When the environment is lacking in stimulation, individuals tend to pay more attention to bodily symptoms which worsens the condition. Cognitive schemas (mental representations) which develop through personal experience with illness can also influence illness perception.

Despite the facts stated above, not everyone who develops a serious physical illness will suffer adverse psychological consequences. This is regulated by the normal process of adjustment to stress called "coping", which can either be adaptive (effective) or maladaptive (ineffective). The acceptance of illness by an individual is an important component in the coping of chronic illness and threats to health. The "self-regulatory model" by Leventhal et al. (Figure 2) is one such model of illness perception which consists of four components:

- · cognitive (mental) representation of illness
- · emotional response to illness and treatment
- · coping directed by the illness representation
- · individual's expectation of the coping outcome

Figure 2. Representation of the Self-Regulation Model (Leventhal, Meyer, & Nerenz, 1980)

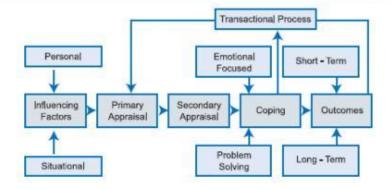


Chronic physical illness is accepted as the stress which arises from the interaction between environmental demands and the resources available to deal with them. According to the "transactional model" of Lazarus and Folkman, individuals faced with an illness assess its likely impact (primary appraisal) and reassess their resources (secondary appraisal).

PSYCHOLOGICAL FUNCTIONING

The perception of illness as a demand or threat depends upon a number of characteristics namely immediacy, ambiguity, uncontrollability, or undesirability, Illness also occurs in a social and interpersonal context, and the involvement of other people contributes to the demand of the situation, Individuals in this situation may accept or be given the 'sick-role' at the expense of their independence and rights. When individuals assess support for responding to illness it is usually focused on personal resources and resources in the social network (family). Personal resources may be in the form of ideas/experiences or personal characteristics whereas social support encompasses emotional support, esteem support and informational support. The family's reaction to illness also has an important impact on the support available.

Figure 3. Transactional Stress/Coping Model (Lazarus & Folkman, 1984).



A common chronic physical illness with high prevalence of psychological disturbances would be 'chronic kidney failure'. which is characterized by a progressive and irreversible loss of kidney function. The manifestations of chronic kidney failure include irritability, insomnia, lethargy, anorexia and seizures, Studies comparing end-stage kidney disease with four other chronic medical conditions (namely diabetes, ischemic heart disease, cerebrovascular disease (stroke) and peptic ulcer disease) found 1.5 to 3.0 times higher prevalence of hospitalizations for psychiatric illness in the end-stage kidney patients.

Dementias and depression were the most common reasons for hospitalization, Adjustment disorders and anxiety states are the other common consequences of this chronic disease. Sexual dysfunction is commonly found among patients with end-stage kidney disease, affecting nearly one-third of medical male in-patients. Disruption in sexual function, which may be physiological or psychological or both, account for at

least a portion of the low mood experienced by patients with this disease.

Although the secondary psychological disturbances can be effectively treated with antidepressants, anxiolytics (antianxiety medication) and psychological interventions (psychotherapy, cognitive behavioural therapy), the definitive treatment for most patients with chronic kidney failure is transplantation or haemodialysis. Symptoms resolve much more completely with transplantation compared to haemodialysis, In general, transplantation is encouraged because of a better quality of life and a greater chance for rehabilitation and symptom resolution.

In conclusion, this article provides the basic understanding about the systems that revolve around the acceptance of chronic illness and also factors that influence health/illness related behaviour.

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The author, Dr. Sivakumar Thurairajasingam, is currently appointed at the Clinical School, Monash University, Johor Bahru as a lecturer and also practises at Hospital Permai as a psychiatrist,



CABARAN PEMAKANAN YANG DIHADAPI PESAKIT-PESAKIT BUAH PINGGANG KRONIK



Oleh Dr. Tilakavati Karupaiah, APD & Dr. Winnie Chee Siew Swee, Pakar Pemakanan, UKM

Pesakit Buah Pinggang Kronik (Chronic Kidney Disease -CKD) yang baru seharusnya mendapatkan bantuan pakar dalam pemakanan mereka, Kebanyakan hospital-hospital utama mempunyai perkhidmatan perunding pemakanan untuk pesakit-pesakit mereka. Jika tidak, pesakit perlu merujuk kepada doktor mereka untuk mendapatkan perkhidmatan perunding pemakanan di hospital-hospital universiti. Perunding pemakanan adalah pakar dalam bidang nutrisi/zat makanan yang terlatih untuk membantu pesakit-pesakit yang menghidap penyakit kronik untuk merancang pemakanan mereka,

Apakah masalah pemakanan yang dihadapi pesakit CKD?

Pemakanan untuk pesakit buah pinggang juga merupakan cabaran kepada pesakit itu sendiri, Ini kerana, zat yang terdapat dalam makanan perlu disesuaikan dengan keperluan pesakit, Selain itu, terdapat makanan tertentu yang boleh menjejaskan kesihatan pesakit perlu Keseluruhannya, perubahan diet adalah rumit dan bergantung kepada keperluan individu pesakit, umur, berat badan, tahap penyakit, faktor-faktor lain yang boleh memudaratkan lagi penyakit CKD dan kandungan darah.

Biasanya pesakit baru akan menolak nasihat tentang pemakanan mereka. Perlu difahami bahawa, pesakit harus berhadapan dengan situasi di mana penyakit CKD yang mereka hidapi tidak boleh sembuh kembali dan perlu melakukan beberapa perubahan kritikal di dalam pemakanan harian mereka, Terdapat juga pesakit yang tidak dapat menerima hakikat bahawa mereka menghidap penyakit CKD. Keadaan ini mungkin menyebabkan pesakit tidak mahu berjumpa dengan pakar pemakanan atau menolak nasihat pemakanan yang diberikan sama sekali. Tambahan pula, faktor-faktor sosioekonomi mungkin merumitkan lagi keupayaan pesakit untuk mematuhi nasihat pemakanan.

Adakah pesakit CKD memerlukan kalori tambahan?

Tidak, pesakit-pesakit CKD tidak memerlukan kalori tambahan, Sebenarnya, mereka mempunyai keperluan tenaga yang sama seperti orang biasa yang sihat, Sebaliknya, situasi-situasi berikut terjadi: Pada tahap awal kegagalan ginjal, selera pesakit adalah normal serta pengambilan makanan tidak terjejas. Apabila kerosakan ginjal semakin teruk dan fungsi penapisannya terjejas, bahan-bahan buangan dalam darah (urea & kreatinin) yang terkumpul mungkin menjejaskan selera, Pada peringkat kritikal, pesakit mungkin mengalami gejala-gejala kandungan bahan buangan yang terlalu tinggi dalam darah seperti rasa loya dan/atau muntah akan mengurangkan nafsu makan atau menolak untuk makan, Apabila pengambilan makanan sentiasa kurang, berat badan pesakit akan mula turun disebabkan kekurangan kalori yang mendadak, Cabaran pada tahap ini, adalah untuk "makan kalori yang secukupnya" bagi mengelakkan kehilangan tisu badan,

Apabila terapi penggantian fungsi ginjal seperti dialisis diberikan, tiada kalori tambahan diperlukan, Pesakit hemodialisis perlulah mendapatkan kalori yang secukupnya bagi menggantikan makanan yang tidak diambil sebelum ini kekurangan pengambilan makanan atau keseluruhannya, Bagi pesakit CAPD (Continuous Ambulatory Peritoneal Dialysis), kalori tambahan diperolehi daripada penampan cecair dialisis (dialysate buffer), Pakar pemakanan akan membuat penyesuaian untuk memastikan kalori-kalori tambahan ini cukup dengan jumlah keperluan tenaga, Jika tidak, berat badan pesakit CAPD akan bertambah.

Adakah pesakit CKD mempunyai keperluan protein khas?

Protein daripada makanan merupakan salah satu zat yang memerlukan banyak penyesuaian di setiap peringkat penyakit buah pinggang, Ini kerana, pengunaan metabolik protein dalam badan bergantung kepada buah pinggang. Apabila buah pinggang semakin merosot, protein yang sedikit ini akan terkumpul sebagai bahan buangan dalam darah dan menyebabkan kelebihan asid dalam badan, Kandungan protein yang tinggi dalam pemakanan juga akan membebankan fungsi penapisan ginjal dan memudaratkan lagi kerosakan yang dialami,

Keperluan protein sentiasa berubah-ubah daripada diet rendah protein pada peringkat awal kegagalan ginjal kepada keperluan yang lebih tinggi dari biasa setelah dialisis dijalankan, Pada peringkat awal, protein dihadkan kepada 0,6g/kg berat badan untuk memastikan kandungan protein cukup untuk membina, membaiki dan mengekalkan tisu-tisu badan, Ringkasnya, diet yang rendah dalam protein biasanya berjumlah 40g sehari. Jika pesakit kekurangan zat yang kritikal, keperluan protein mereka mungkin tinggi sedikit iaitu 0.75 g/kg berat badan.

Pesakit yang sedang menjalani hemodialisis (1,2-1,3g/kg berat badan) dan CAPD (1,3-1,4g/kg berat badan) mempunyai keperluan protein yang lebih tinggi untuk menggantikan kehilangan protein semasa dialisis, Pesakit seharusnya berjumpa dengan pakar pemakanan bagi mendapatkan nasihat tentang keperluan protein dan cara melaksanakan pelan pemakanan seharian, ini kerana kualiti protein adalah penting: Protein berkualiti tinggi mengandungi campuran asid amino perlu dari sumber haiwan seperti daging ayam, lembu, kambing ikan. telur dan hasil dan tenusu. Protein yang kurang kualitinya boleh didapati dari sumber tumbuhan seperti kacang soya, dal, kacang dan pelbagai tumbuhan kekacang lain, Kekurangan ini disebabkan oleh kekurangan satu atau lebih asid amino perlu. Pesakit dinasihatkan untuk mendapatkan campuran makanan berprotein yang betul dengan memastikan sekurang-kurangnya 50% jumlah protein adalah protein berkualiti tinggi.

NKF Bids Farewell to Dr. N. Ganesan



(L to R) Goh shaking hands with Dr. Ganesan with Dr. Shanker, Medical Programme Manager, looking on.

As one of the founder members of the National Kidney Foundation of Malaysia (NKF), Dr. N. Ganesan has finally made the difficult decision to retire as Chairman of the Patient Selection and Welfare Committee, a voluntary job he undertook for the past 34 years. Mah Ah Noye, Manager, Welfare Unit, said it was indeed a great loss to NKF as his input and advice benefited dialysis patients and provided the Committee with valuable information on which to base decisions related to the welfare of dialysis patients.

According to Goh Seng Chuan, CEO, NKF, as a founder member, Dr. Ganesan had contributed tremendously to the psychological and social well-being of patients and had played a pivotal role in the selection of poor and needy patients and engineering various programmes to financially assist those who could not afford the high cost of dialysis. At a farewell ceremony in NKF, a token of appreciation was handed over to Dr. Ganesan together with a Letter of Appreciation for the many years of service provided to dialysis patients.

Official Opening Pusat Dialysis Tuanku Syed Putra-NKF Dialysis Centre, Kangar, Perlis



Group photo taken at Tuanku Syed Putra-NKF Dialysis Centre official opening

he official opening of the Tuanku Syed Putra-NKF Dialysis Centre marked the realization of the wishes of YMM Tuanku Raja Perempuan Besar Perlis, Tengku Hajah Budriah binti Al-Marhum Tengku Ismail to assist dialysis patients as her late husband, the former Ruler of Perlis, Al-Marhum Duli Yang Maha Mulia Tuanku Syed Putra Jamalullail suffered from End Stage Kidney Failure till his death, YMM Tengku Hajah Budriah said dialysis was one form of treatment for End Stage Kidney Failure and apart from dialysis she hoped members of the public would come forward to donate their organs to reduce the suffering of patients and offer the hope of leading a quality life.

The dialysis centre was built at a cost of RM1.1 million, fully funded by the Yayasan Al-Bukhary, headed by Tan Sri Syed Mokthar Al-Bukhary, with support from Dato' Seri Radzi Tan Sri Sheikh Ahmad. The dialysis centre, which began operations on 13th July 2005, has 22 patients on dialysis and financial assistance amounting to RM 6,720 has been given to 4 poor patients. With 15 haemodialysis machines, the cost of running the centre would be undertaken by NKF.

Light Up A Life - Kamahl in Concert

In aid of the Tun Abdul Razak - NKF Dialysis Centre in Pahang





YB Datuk Dr. Haji Abdul Latiff Bin Ahmad receiving a token of appreciation from Tan Sri Dato' Dr. Abu Bakar Suleiman, Dr. George Ananda in the background.

he poor and needy kidney failure patients in Pahang can now look forward to affordable dialysis treatment to serve their needs better with the funds raised from the special performance by Kamahl, a Malaysian born singer, based in Australia. As the winner of numerous international accolades Kamahl, based in Australia has distinguished himself as a singer. The proceeds from the show on 19th May 2007 at Crown Plaza Mutiara, Kuala Lumpur, will be used to build the very first dialysis centre of NKF in Pahang, YB Datuk Dr. Haji Abdul Latiff bin Ahmad, Deputy Minister of Health, representing the Deputy Prime Minister was the Guest of Honour. The night was filled with the melodious voice of Kamahl, who had the audience mesmerized throughout the performance. NKF has identified a strategic location for a well-equipped and professionally managed dialysis centre in Kuantan to provide dialysis for poor and needy patients in order to make available to them affordable dialysis. This is also part of NKF's ongoing effort to make dialysis treatment not only more affordable but also within reach of the lower income group.

TAHUKAH ANDA BAHAWA...

- Sesiapa pun, sama ada tua ataupun muda boleh menjadi seorang penderma organ & tisu. Mereka yang berusia kurang daripada 18 tahun perlu mendapatkan kebenaran ibubapa atau penjaga terlebih dahulu.
- Pendermaan organ adalah penghadiahan bahagian tubuh badan seseorang untuk tujuan pemindahan selepas ianya meninggal dunia.
 - Pada umumnya, pemindahan organ yang biasanya dijalankan adalah buah pinggang, jantung, hati, paruparu dan pankreas, manakala, tisu-tisu yang boleh dijalankan pemindahan adalah mata, tulang, kulit dan injap jantung.
 - Semua agama termasuk Islam, Kristian, Buddha, Hindu dan Sikh mengiktirafkan pendermaan organ dan tisu sebagai satu amalan yang mulia.
 - Penderma organ yang menderma semua organ dan tisu boleh membawa perubahan kepada nyawa 10-15 orang.
 - Lebih kurang 15,000 orang sedang menunggu pemindahan buah pinggang akan tetapi peluang untuk memperolehi pemindahan ini adalah amat tipis.