

Transplant news

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Editorial

Professor Jerome Loveland
Editor

Having just attended a large international transplant meeting, it is always good to return home in the knowledge that our local transplant units provide a level of clinical service to our patients equal to those in other more developed countries.

However, the stark reality is that a large proportion of this care is funded and driven by the private sector, both in terms of finance and logistics. Dr David Thomson, from the Transplant Unit at Groote Schuur Hospital, University of Cape Town, gave a very sobering national overview of transplantation in South Africa, highlighting 2 major concerns, these being the growing gap between patients listed for transplantation and organ availability, as well as the relative stagnation of transplantation in our Government Hospitals.

Whilst we are constantly looking for options that increase organ availability, for example splitting a liver into 2 separate useable pieces, and living related kidney and liver donation, demand still far exceeds supply, and it is incumbent on all of us, including our Government, to continue community education around the value of organ donation.

Whilst policy decisions and targeted intervention have been shown to improve donation rates, it is often the more peripheral, spontaneous actions that have the greatest impact on encouraging individuals to donate their organs.

There are 2 examples that always spring to mind. Firstly, when transplant recipients tell their personal stories, narrating their hardships and challenges whilst waiting for an organ, in comparison to the life-changing event of the transplant itself, one cannot help but feel inspired to donate one's organs. The second massively persuasive event is the Transplant Games. Watching these athletes compete and enjoy life to the full having received their transplanted organ, embracing the competitive spirit of the games, yet competing as one family, well, if that doesn't convince one to become an organ donor then nothing will!

This edition of Transplant News touches on both of the above inspirations, amongst other interesting articles. If you are not an organ donor yet, become one today!

Visit the Organ Donor Foundation website at: www.odf.org.za or call Toll Free: 0800 22 66 11 to register.

South African Transplant Sports Association National Games 2014

9-11 October 2014

Stellenbosch

For more information, see page 3 or visit:
www.transplantsports.org.za



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Kidney transplantation



Dr Gerrit Rossouw
Nephrologist
Universitas Private Hospital
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When advanced kidney failure (stages 4b and 5 of Chronic Kidney Disease [CKD]) is diagnosed in a patient, the treating nephrologist has to ask some important questions about the further management:

1. Is this patient a candidate for any form of renal replacement therapy? For example if the patient has a terminal disease with a very poor 6-month prognosis, no dialysis or transplant may be done.
2. If the patient is fit for renal placement therapy, the next question will be: is this patient a candidate for a possible pre-emptive transplant if a donor is available? This means a transplant before starting any form of dialysis. This is the ideal choice of management.
3. If no donor is available, the patient then needs to decide between the different forms of dialysis. This group of patients is then evaluated for possible future kidney transplant, and if they are found suitable they are listed on a deceased donor waiting list. Due to the severe shortage of deceased donors, the waiting time can be very long.
4. Dialysis can either be In-Centre (in a dialysis unit) or at home:
 - In-Centre: usually haemodialysis – an AV fistula needs to be created before dialysis is started.
 - Home dialysis:
 - Peritoneal dialysis (CAPD or APD)
 - Home haemodialysis

We will now only discuss option 2 – the option of a potential living donor.

There are different groups of living donors, but the most common group will be the donors that are well known to the recipient:

- Immediate family (mother, father, brother, sister)
- Extended family (nephew, niece, aunt, uncle, etc.)
- Spouse (husband or wife). This group is also known as emotionally related donors
- Close friends

For one of these to be a potential donor, they need to be healthy. This is sometimes a major problem if there is a familial kidney disease, for example autosomal dominant polycystic kidney disease (ADPKD) that may affect other family members.

The next important step is for the donor to make sure that his or her blood group will allow a kidney donation to the



recipient, in the same way as a blood transfusion. This needs to be resolved before any further work-up can be done.

If the potential donor thinks that he or she is healthy and it is confirmed that he or she has the correct blood group, then the donor can make an appointment with the nephrologist.

The nephrologist will then do a complete clinical assessment to screen for any major clinical abnormalities. A complete set of tests will follow later in the evaluation to make 100% sure that the donor is healthy for donation. On these later tests, a potential abnormality can be found that will exclude this person for donating. Remember, these tests are done to protect the donor from future harm.

On this first visit the nephrologist will make sure this potential donor does not also suffer from a chronic disease that may affect his or her kidney function in the future (important diseases will be diabetes or hypertension). The donor must also not suffer from a chronic viral infection (HIV, Hepatitis B or C, etc.) that can be transferred to the recipient. Due to the immunosuppressive medication that the recipient uses after the transplant to prevent rejection, they are more prone to infections and less able to recover.

We also ask about the donor's habits – here we don't want the donor to be addicted to any drugs - the most common problem is cigarette addiction! The donor needs to stop smoking, otherwise we will not continue with the evaluation. The donor needs to be more than 21 years of age (some will accept more than 18 years). The upper age limit is not as well defined.

We must remember, as we grow older, so will our organs also become older. A person older than 60 years may potentially have a glomerular filtration rate (GFR) less than 80 ml/min, which will exclude this donor from donating. But if this donor wants to donate to another person of similar age, this may be possible. On this evaluation the nephrologist will again confirm that the donor has a normal blood pressure (this blood pressure will be confirmed on different occasions, at least 3 times) and if in doubt other tests will be performed to evaluate the blood pressure (24 hour ambulatory blood pressure monitoring). We also check the urine to make sure there is no blood or protein in the urine, because this can be a sign of an underlying kidney disease that will need further evaluation.

On this first visit we will also do the weight and length of the donor. With this information we calculate the donor's body mass index (BMI). We don't want the donor to be overweight. The BMI needs to be less than 30. This is sometimes a major problem for the family. Everything else may be correct, but if the weight is not correct, we cannot continue. It can also take some months for the donor to reach the target weight.

If the donor is found to be medically suitable for a kidney donation, the donor is then sent to confirm his or her blood group and to do a HIV test. If the blood group is found to be correct to donate for that particular recipient and the donor is HIV negative, the next tests are completed. This is usually a tissue typing and white cell and red cell cross matching. These are important immunological tests to determine if that donor can donate to that recipient and how good the matching is between donor and recipient. This is why donation from direct

family members (living related donations) is better, because the immunological matching is far better. This will impact on how long the transplant organ will function, the better the matching, the better the long-term graft survival.

After all of this, then the rest of the tests will follow, to evaluate and to make sure this donor is a suitable donor. On these later tests a potential abnormality could be found that may impact on the donor's ability to donate. This is all done to protect the donor from future harm. During this evaluation the donor also undergoes a psychological evaluation, mainly done to rule out any pressure to donate (any coercion), to discuss the psychological impact of living with one kidney, and to rule out any psychological disease that maybe a problem with kidney donation.

Only after all of these tests will the donor eventually be finally found suitable to donate.



11th National Transplant Games - October 2014



*Mrs Heilie Uys
SATSA Secretary
St. Francis Bay*

South Africa's transplant athletes will descend on Cape Town and Stellenbosch from 9 to 11 October 2014 to compete at the 11th National Transplant Games, hoping to qualify for the World Transplant Games. This event is presented by SATSA (The South African Transplant Sports Association). SATSA is recognized by the Department of Sport & Recreation and SASCOC and is a Member of the World Transplant Games Federation (WTGF), recognized by the IOC.



The picturesque setting of Coetzenburg for this year's Games is sure to inspire athletes from ages 5 to 80 years, to underline the talent that will represent South Africa in Mar del Plata, Argentina in 2015. This year has a full programme of events set for the Cape Town and Stellenbosch area and surrounds.

"The National Transplant Games is always the highlight on the transplant calendar," WP Transplant Sports Association chairman and chairman of the Local Organizing Committee Stan Henkeman explained. "It is the point in every transplant athlete's year where they strive to be at their best, ensuring they gradually improve their own performances, while keeping one eye on their goals to qualify for Argentina."

The National Transplant Games will open on 9 October 2014 with the arrival and registration of athletes and also the AGM of SATSA and will be followed by two days of tough competition between the athletes. The Games vividly demonstrate the success of organ transplantation and the ability of transplant recipients to lead healthy, normal lives. The public is invited to come and experience the Celebration of Life which all athletes will display at these Games.

For more information contact the SATSA Secretary Heilie Uys:

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- Cell: 082 465 0935
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- Visit website: www.transplantsports.org.za

Real people: Maria Florença

Maria Lucinda Ramos Florença
Kidney transplant recipient
Ventersburg

Name: Maria Lucinda Ramos Florença

Occupation: Self-employed

Family: My husband, Orlando, three sons, Octavio, Marcelino, Orlando and my daughter, Maria Inés

Interests: To be with my family and to have fun

Likes: Reading, music, cooking, gardening, watching reality shows

Tell us how you came to have peritoneal dialysis

I don't know, it's not genetic. I am the first one in the whole family to have any kidney-related disease.

In 2008, after the birth of my son, I started feeling very sick with lots of headaches, feet and hand cramps and being very tired most of the time. Finally in 2010, I found out I had kidney failure and I was referred to Dr G Rossouw.

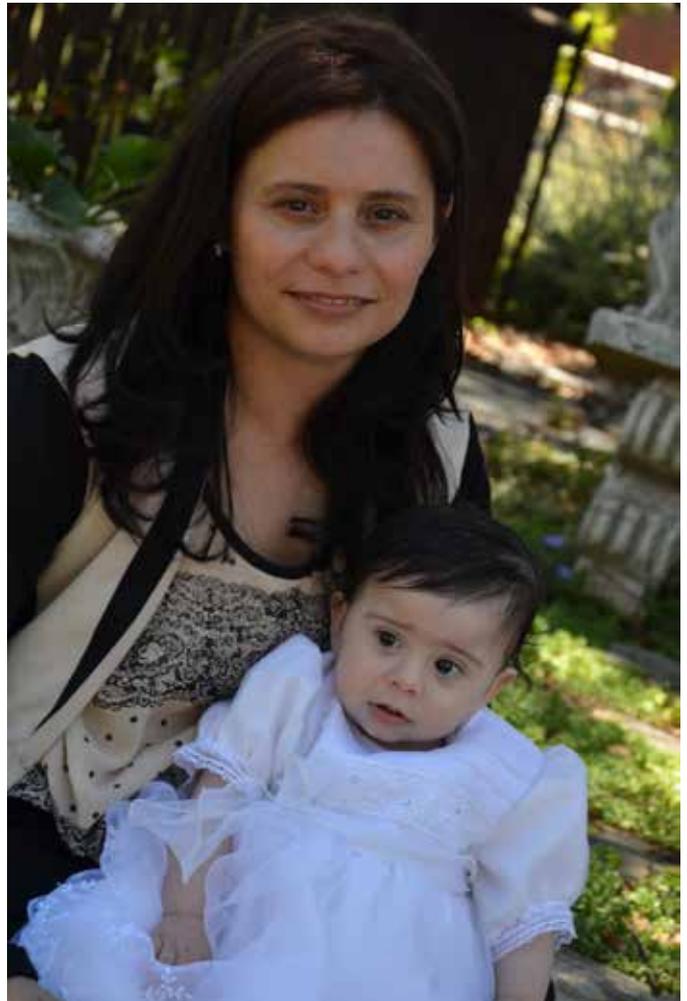
Tell us your experience as a peritoneal dialysis patient?

At first it was very hard to accept. Then I realised I had no choice, but with time I adapted to the treatment and I started feeling better. I had to manage my time better during the day so that I could do 10 hours of dialysis every day and be ready by 6 a.m. in the morning to help my sons get ready for school. It needs a lot of dedication to do PD at home because everything needs to be very clean to prevent infections.

What are the complications, risks and benefits of peritoneal dialysis?

Complications and risks are different for each person. For me, it was making sure not to get any infections.

The benefits of PD is you are free the whole day to do what you need to do, like going to work and attending your children's sport activities in the afternoon, without worrying about your treatment during the day, because you do it at night, starting at 7 p.m. for cleaning and warming the liquid before connecting yourself on the machine. Then you do 10 hours during the whole night and you will be done by 6 a.m. in the morning. The later you start, the later you finish.



Tell us about your experience falling pregnant while on dialysis (a very unique experience)

First when I found out I was pregnant it was a shock to me, then I felt scared because being on PD dialysis I did not know how I was going to handle it. But with all the help I got from the doctor and nursing staff of PD unit, I just took it one day at a time and I was also very excited because I was expecting a little girl after having 3 boys.

When did you become the proud mother of a beautiful, healthy daughter?

I was 32 weeks pregnant when she was born on the 25 October 2012, the most gorgeous little princess

When did you have a Kidney transplant?

On the 5th of April 2014

How has having a transplant changed your life?

It's been over a month now and I am feeling very energetic. I can now do things more relaxed without having to worry about time. I have more time for my children and can look after them better. I feel normal again and eat food that I could not before.

Have you found an improvement in your quality of lifestyle?

Yes. I feel healthy again.

What are the challenges of your lifestyle as a transplant patient?

Not to forget to take my medication and to try to prevent any infections.

What advice would you give to those who have been newly transplanted?

Take it easy in the beginning and learn all you can about looking after your new kidney and follow all the advice your doctor gives you.

What resources have helped you cope with transplantation (books, websites, and support groups etc)?

Some websites are definitely where you can get a lot of information. And some information from my doctor as well.

What advice would you give to people contemplating having a transplant?

Never despair or give up hope because when you least expect it you will get that phone call that you have been waiting for.

To my donor's family

I want to thank your family for this gift of life. I have personally been praying for your family since I received the transplant. I know that the grief that you feel must be awful, but I hope that it helps you to know that your choice has dramatically improved my life and my family's. I thank God on daily basis for your family and for your gift of life.

I doubt that it was an easy decision, but it is certainly one that I will always be grateful for and it will have a wonderful impact on me and my family for years and years to come.

With all my heart, I wish you peace, love, and above all, the Lord's abundance blessing upon you.

“Take it easy in the beginning and learn all you can about looking after your new kidney and follow all the advice your doctor gives you.”

To Dr Rossouw

I want to express my extreme gratitude and thank Dr Rossouw for all he has done and continues to do for me. Your dedication, professionalism and generosity has helped me and my family and we are very grateful. We wish you and your team the very best in the future.

To the nursing staff

I want to say thank you to the nursing team in the PD dialysis centre in Netcare, Sister Lynette and Ansuné who looked after all my dialysis needs and were all always ready and available to help me and give me their support through all my ups and downs physically and emotionally. I also want to thank the nursing team in NetCare for nursing me and for looking so well after me.

Exercising after transplant



Sue Naude Bsc Physio
Physiotherapist
Wits Donald Gordon Medical Centre
Johannesburg

Transplant surgery brings with it a number of challenges and queries both before and after. One of the queries is the role that exercise plays after the event. Initially this might sound like a very scary concept considering the surgery you have been through. This article should alleviate some of the fears and hopefully show you the benefits and improvements your life will have in introducing exercise back into it.

Why should I exercise?

It has been found that exercise post surgery results in faster recovery than where exercise is not introduced.

Benefits include:

- Improved circulation
- Improved energy levels
- Lower blood pressure
- Improved muscle tone, strength, balance and joint flexibility
- Strengthened bones
- Reduced stress, tension and depression
- Boosted self-esteem
- Improved sleep
- Maintained healthy body weight

Getting started, this is the hardest part!

You are de-conditioned pre surgery resulting in lack of muscle strength; you haven't exercised in a long time and have no idea where to start.

Starting point should initially be an all clear from your doctor/medical team. Your health care provider can help you find a program that matches your level of fitness and physical condition.

Initially you will be seen in hospital by the physiotherapist who will get you started on mobilizing and gentle exercises. This will focus on mobility and improving strength, endurance and flexibility. It is important to start this as soon as possible (as soon as the doctor gives the all clear). It has been shown

that those who exercise have faster recovery and less post-op complications.

Exercise is divided into three types:

Stretching: This improves range of motion and flexibility and helps prevent injury.

Cardiovascular. This type of exercise strengthens the heart and lungs and improves the body's ability to use oxygen. This includes walking, jogging, bicycling, and low-impact aerobics or water aerobics.

Strengthening: Repeated muscle contractions (tightening). For the first eight weeks an exercise band should be used (theraband). Thereafter light weights can be introduced. (Consult your healthcare provider)

How often should I exercise?

In general, to achieve maximum benefits, you should gradually work up to an exercise session lasting 20 to 30 minutes, at least three to four times a week. Exercising every other day will help you keep a regular exercise schedule.



When can I start exercising?

While in the hospital, you will be encouraged to mobilise and walk as soon as is medically safe. Walking is the best form of exercise after transplantation, as it helps reduce swelling and expedite the recovery process. Around four to six weeks after surgery, other types of exercise can be added. After about six to eight weeks, assuming that the surgical wound has healed well and you get approval from your medical team, you can begin nearly any form of exercise. However, contact sports should be avoided.

What should I include in my programme?

Every exercise session should include a warm-up, a conditioning phase, and a cool down.

Warm-up includes stretching and range of motion activities. The **conditioning phase** is where benefits of exercise are seen, this is where calories are burned, muscles are strengthened and endurance achieved. In this phase you should monitor the intensity of the activity. This should be specified by your healthcare provider. Over time, you can work on increasing the duration of the activity.

The **cool-down** phase allows your body to gradually recover from the conditioning phase. Your heart rate and blood pressure will return to near-resting values. Cool-down does not mean to sit down. Do not sit, standstill, or lie down right after exercise. This may cause you to feel lightheaded.

General exercise guidelines

- Gradually increase your activity level, especially if you have not been exercising regularly.
- Choose an activity that you enjoy
- Wait at least 1½ hours after eating a meal before exercising.
- Exercise at a steady pace. (Able to talk during exercise)
- Make it regular exercise, it will soon become part of your lifestyle.
- Keep an exercise record.

Stop exercising and rest if you:

- Have chest pain
- Feel weak, are dizzy
- Have unexplained weight gain or swelling (call your doctor right away)
- Have pressure or pain in your chest, neck, arm, jaw, or shoulder
- Have any other symptoms that cause concern
- Call your health care provider if these symptoms do not go away.

Exercise precautions

- If you are too tired, change the exercise that day to one of a lower intensity but if you feel overtired do not exercise at all.
- Avoid heavy lifting and heavy chores. These should not be done for the first eight weeks.
- Avoid even short periods of bed rest after exercise, since it reduces exercise tolerance. Rather sit in a comfortable chair
- Avoid exercising outdoors when it is too cold, hot, or humid.
- Avoid extremely hot or cold showers after exercise.
- Avoid areas where infection can be high i.e. gyms, always wipe down equipment
- Reduce your activity level if your exercise program has been interrupted for a few days.
- Do not exercise if you are not feeling well or have a temperature. Consult your healthcare provider as to when to start again.
- If you are short of breath, slow down or rest. Keep your feet raised, or elevated, when resting. If you continue to have shortness of breath, call your doctor.
- If you develop a rapid or irregular heartbeat, or have heart palpitations, rest. Check your pulse after resting for fifteen minutes. If your pulse is still high call your doctor for further instructions.
- Do not ignore pain, ask your healthcare provider for specific guidelines

This article serves as a guideline for exercising post transplant. Your medical transplant team will give you more specifics in accordance with the type of transplant you have had and according to your condition. Always consult with your team.

Waiting for a heart and lung transplantation



Sr. Marlize Frauendorf B. Cur (Hons Emergency and Trauma Nursing)
Heart and Lung Recipient Co-ordinator
Netcare Transplant Division
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Waiting for a life-saving transplant is probably the most difficult phase in a person's life. It can put enormous stress on the patient and its relatives. Fear, anxiety and uncertainty are normal reactions. Since this can be a frustrating and demanding time, it is recommended to make use of support services offered, e.g. the psychologist and support groups.

Waiting period

Once a potential recipient qualifies for a transplant the patient is placed on the regional heart or lung transplant waiting list. The general waiting period is between six months and five years. The recipient eventually chosen for a transplant is the person with the best match to the available donor heart or lung/s. Recipients are not selected because of ranking on the list, although waiting time on the list is taken into consideration. Matches are chosen on blood group, size and medical urgency. Many patients awaiting transplantation find this period very difficult as there is no way of knowing when a matching donor will become available.

The goal for both you and the medical team is to maintain you in the best possible medical and psychological condition. This will not only affect your health and quality of life before the transplant, but it will also greatly improve your post transplant recovery.

It is important to stay in touch with your transplant co-ordinator during the waiting period. We request that you attend your regular follow-up appointments and notify your co-ordinator when your condition changes. Let the co-ordinator know if you are running a fever or have an infection. It is important for us to know this, because having

a transplant during a period of active infection is dangerous. Follow your treatment routine precisely – it truly is a matter of life and death.

Also report any of the following changes to your transplant co-ordinator:

- Any illness
- Any changes in medication
- Any hospitalization
- Any change of doctors
- Any blood transfusions you receive
- Any change of your address or telephone numbers
- Any change of your family or work situation.

Be ready

- Pack a personal bag and have it ready to bring to the hospital. You may visit the hospital a couple of times while waiting for your heart transplant due to fluid retention, infections, etc.
- Initially you will only need toiletries in ICU, but once you are transferred to the ward your family can bring your other necessities (refer to Issue 47 for a check list).
- Be actively involved in a rehabilitation or exercise program. Stay as active as possible.
- Buy a thermometer, a scale, and if possible an automatic blood pressure cuff. You will need these when you arrive home after the transplant.
- Read all the information your transplant team gives you. Ask questions if you are uncertain of anything.

For more information on Heart or Lung Transplantation please contact the Netcare Transplant Division on 011 489 1272 or email transplant@netcare.co.za.

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