



Transplant News

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Editorial Board



Professor Jerome Loveland

Academic Head
Department of Paediatric Surgery
University of the Witwatersrand
Transplant Surgeon
Wits Donald Gordon Medical Centre
Johannesburg



Professor Russell Britz

General Vascular
Surgeon
Wits Donald Gordon
Medical Centre
Johannesburg

Transplant News Production

Production Editors: Ann Lake Publications:
Ann Lake/Helen Gonçalves
Design: Jane Gouveia
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Enquiries: Ann Lake Publications
Tel: (011) 802 8847
Fax: 086 671 9397
Email: lakeann@mweb.co.za;
www.annlakepublications.co.za

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Editorial

Professor Jerome Loveland
Editor

Embedded within this edition is an article written by Candice Cowen, which explores the relationship between illness-related uncertainty and hope, feelings that are only too common after the diagnosis of your disease and journey towards, through and after transplantation. Obviously an absolute reality, she brings you to terms with why these emotions occur, and how to best deal with them. That said, the possible outcomes of “hope” are endless...

The lead article is particularly pertinent in this regard, and certainly piqued my interest in a seldom thought about aspect, certainly for our female patients: pregnancy. One automatically associates renal failure with the very real risk of death, and the complete turn around that a kidney transplant gives to the recipient – a new lease on their own lives, on so many levels.

As fit and healthy people, one does not even consider not being able to fall pregnant, and this is something that had never crossed my mind before, the inability to conceive as a result of one's renal failure. What a gift reversing that pitfall must be!!!! First a kidney, then a pregnancy!

As exciting as this is, please ensure that you read Derek Miller's article extremely carefully - your doctor's advice is critically important before embarking on this life-changing endeavour.

As ever it is the “real life”, “True Story” patient experiences that are a constant inspiration. None are more inspiring than that of a donor tribute, in this case written by Clauwdet Lok – but please, read it for yourselves. The light at the end of the tunnel, for the countless transplant recipients, is the “Gift of Life” from your donor, giving hope to patients, their family and the donor family alike.



20th World Transplant Games, Mar del Plata, Argentina - Read more on page 8

Pregnancy in patients with chronic kidney disease and kidney transplantation

Dr Derek Miller
Physician
MediClinic Constantiaberg
Cape Town



Patients with chronic kidney disease may not only have difficulty becoming pregnant but are less likely to carry a successful pregnancy. Pregnancy may also cause kidney function to deteriorate.

- Patients with a creatinine level below 130 $\mu\text{mol/litre}$ are usually able to fall pregnant and have a successful pregnancy.
- When the creatinine level is between around 130-250 $\mu\text{mol/litre}$ it is less likely that patients can become pregnant, the risk of severe hypertension developing during pregnancy and the risk of losing the pregnancy are high. There is also a significant increase in the possibility of the kidney function deteriorating during and after the pregnancy.
 - Up to 10% of patients with kidney function in this range will reach end-stage kidney failure and require dialysis within 12 months of pregnancy.
- Patients with a creatinine above 255 usually have amenorrhea and are not usually able to conceive. The likelihood of carrying a foetus to term is extremely low and the likelihood of deterioration of kidney function during pregnancy is very high.
- The frequency of conception of women of childbearing age who are on dialysis is between 0.3-1.5% per year. In recent years more dialysis patients have been able to have a successful live birth by increasing the duration and frequency of haemodialysis therapy.
 - Most patients on haemodialysis received about 12 hours dialysis per week but if this is increased to between 24-36 hours per week the possibility of carrying the pregnancy successfully may increase to above 80%.

Could I have a baby after my kidney transplant?"

Most women regain fertility and are able to become pregnant after a kidney transplant and it is essential that they receive counselling regarding contraception.

Patients with a kidney transplant are usually using medications which are potentially toxic to the foetus and this needs to be considered when planning pregnancy. As with other patients with chronic kidney disease the ability to become pregnant and have a successful pregnancy depends on the level of kidney function.

In a transplant patient with:

- a creatinine less than about 130 pregnancy is usually relatively uncomplicated and successful.

- If the creatinine is between 130-250 pregnancy is not advisable but may be possible with careful management.
- When the creatinine is above 250 pregnancy is usually not possible.



The possibility of pregnancy should be discussed in detail with the transplant physician and be carefully planned.

Can I fall pregnant while using immunosuppressive medication?

- **Cyclosporine** - in higher doses it is known to result in growth retardation and in animal studies problems have been identified but no adequate studies are available in human pregnancies. It is generally advised to discontinue this drug during pregnancy but it may be necessary to continue it to avoid rejection but lower doses are advised with careful monitoring
- **Tacrolimus** - available studies during pregnancy shows that up to 70% of pregnancies are successful and uncomplicated.

It is generally felt that patients should avoid pregnancy during the first year after a live donor kidney transplant and for at least 2 years after a cadaver kidney transplant

It is believed that it can cause malformations in babies when higher doses are used. It is advised that it be used at lower doses or preferably discontinued if it is safe to do this.

- **Mycophenolate mofetil** - this is contraindicated during pregnancy because of adverse effects on foetal development. It is advised that this drug be switched to a safer agent during pregnancy (usually azathioprine).
- **Sirolimus/Everolimus** - is contraindicated in pregnancy because animal studies have shown significant foetal abnormalities.
- **Azathioprine** - this drug has been used extensively and for many years and is generally felt to be the safest form of immunosuppression together with prednisone during pregnancy. Careful monitoring of the dosage and the white blood cell count are important.
- **Other drugs: ACE inhibitors and ARBs** - these drugs are commonly used for the treatment of hypertension and contraindicated during pregnancy. Patients that are planning pregnancy should be switched to safer alternatives and patients that become pregnant while using them should have them discontinued as soon as possible.

General considerations

It is generally felt that patients should avoid pregnancy:

- during the first year after a live donor kidney transplant
- for at least 2 years after a cadaver kidney transplant.

The possibility of pregnancy should be discussed in detail with the transplant physician and be carefully planned. This will involve:

- careful assessment of kidney function to assess possible risk
- assessment of blood pressure and ensuring optimum control
- adjustment of immunosuppression therapy and other medication to avoid drugs which may be toxic to the foetus.

The obstetrician and transplant physician need to work closely during pregnancy. Kidney function and proteinuria as well as blood pressure need to be monitored regularly.

Summary

Patients of childbearing age with kidney failure or kidney transplant need to be counselled regarding:

- pregnancy and
- need to receive appropriate contraception.

When the kidney function is good it is acceptable to consider pregnancy but patients with average or poor kidney function should be discouraged from pregnancy. In general, if the serum creatinine is above 250 or if there is protein in the urine the risk of pregnancy is significantly higher.

In preparation for pregnancy drugs which are potentially toxic to the foetus should be discontinued and blood pressure needs to be optimally controlled.

Once pregnancy is confirmed careful monitoring of kidney function, urine protein levels and blood pressure are essential. These can be managed initially but if they deteriorate significantly early delivery may be required.

Patients need to understand that pregnancy may result in:

- a decline of kidney function which may result in progression to
- end-stage kidney failure
 - loss of a transplant kidney and the
 - return to dialysis.

Loss of a foetus will always be traumatic and severe complications during pregnancy may also place the patient's life at risk.

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The relationship between Hope and Illness-Related Uncertainty...

*Ms Candice Cowen, B.A. Child and Family Psych (UJ), B.A. Hons Psych (UJ), M.A. Clin Psych (Unisa)
Psychologist in private practice Sandton*



This may seem to some a very contradictory relationship at first glance. However, to understand how a relationship can exist between two very different 'emotional' experiences and to understand the impact it has on Emotional Adjustment and Adherence, we need to put them into context.

Being diagnosed with an illness can be the start of a long and challenging journey, for some. Initially individuals and their families may go through a period of feeling 'stuck' or helpless.

Individuals are forced to, on both a cognitive and emotional level, process and digest the immediate and potential long term implications of the illness, procedures and treatments. Individuals may start to experience **uncertainty** and worry. **Uncertainty** that often creates many questions for the individual and family members, which are mostly unanswered. This **uncertainty** is further stressed by the medical aspect of the illness which includes regular visits to doctors and hospital. These visits require individuals to undergo ongoing medical investigations which can often be uncomfortable, intrusive and painful. There is also the aspect of having to have entrust professionals and medical science for a successful outcome.

The start of such a journey can be very confusing and frustrating and can lead to an individual or their family members to experience intense feelings of **hopelessness** and despair and develop secondary psychiatric conditions such as depression, anxiety or acute traumatic stress disorder.

The study of human nature, behaviour and survival skills has led to theories of how human-beings get through difficult and life challenging circumstances and has helped towards developing an understanding of how intense feelings of hopelessness and despair are countered. Findings from these studies help us understand the emotional experience and how **hope** has its place in relation to illness-related **uncertainty**.

Hope is a common activity for all humans. Studies have shown that when an individual is faced with a life threatening situation, **hope** may function as a lifesaving force for individuals who are overwhelmed by despair and hopelessness.

For some, **hope** provides a reason to go on living. It may help individuals become goal orientated and maintain motivation, as well as positive expectations. More importantly **hope** acts as a buffer to secondary psychiatric conditions that can develop.

Hope also extends itself to the family of the individual by unifying individuals of the family through a shared emotional experience that helps them cope with the **uncertainty** that illness creates.

It can be said that both the experience of **hope** and **uncertainty** is an inevitable and common experience related to illness. What is important to remember that some individuals may experience **hope** or **uncertainty** in varying severities at different stages in their journey or experience one of these experiences and maybe not both simultaneously. There is no hard or fast rule when it comes to an emotional experience.



Understanding how Hope and Uncertainty are created

Emotional experiences such as **hope** and **uncertainty** are created by circumstances/situation (illness), perceptions and our interpretations (how we perceive an event or circumstance), and feedback from physical sensations (feelings, bodily sensations) in a moment. We then tend to categorize and label our feelings and this results in an experience.

Emotions are important as they tell us how to act or behave in a situation. They help us attribute meaning and understanding of an experience, which gives important feedback for how to respond to future experiences.

Awareness of emotional experiences such as **hope** and illness-related **uncertainty** helps us understand the impact that these experiences have for individuals with regards to their emotional adjustment and adherence. An individual's emotional adjustment to a diagnosis or what the road

ahead looks like regarding their treatment is very important. Psychologically, emotional adjustment plays an important role in the stages an individual goes through which can include trauma, bereavement or loss, and/or acceptance and motivation. Depending on how an individual processes this adjustment, it will in turn impact the individual's adherence to their treatment positively or negatively.

The Impact that illness- related Uncertainty has on Emotional Adjustment and Adherence

The following example is to illustrate how uncertainty can be created and how it influences an individual's emotional adjustment and adherence to treatment.

Patient X (who was diagnosed with a terminal illness last year) goes into the hospital for her weekly treatments and every week she sees another Patient Y who has the same diagnosis and is receiving the same treatment from the same doctor. However, every time Patient Y comes out of the doctor's rooms Patient X notices that she is smiling. Patient X always feels overwhelmed and cries when she leaves. Patient X thinks that this must mean that Patient Y is doing better in terms of progress than Patient X or is even receiving better treatment.

Patient X starts to feel anxious and constantly worries about whether the treatment is working for her. She becomes consumed by this worry and feels that no one understands what she is going through. She feels lonely and becomes sad and depressed. Patient X then becomes very despondent about the future and becomes reluctant to adhere to her treatment as she doesn't really believe it will work for her.

The Impact that Hope has on Emotional Adjustment and Adherence

The following example is to illustrate how hope can be created and how it influences an individual's emotional adjustment and adherence to treatment.

Patient X has recently been diagnosed with a terminal illness. It requires constant medical treatments and a life changing life style. She experiences physical, cognitive and emotional demands daily due to her illness.

She has been through the initial stages of denial and anger towards her health status. She found herself being consumed with worry and an overwhelming sense of dread.

Patient X has found a way to cope with her illness by experimenting with what coping skills work for her and what doesn't. She has decided to consciously choose to hope for a development in her treatment to happen that will help her progress. As a coping skill she has had to learn the capacity to tolerate and express concerns and emotions not just ignoring the ugly feelings. Being able to discuss the anxieties, uncertainties and fears, losses and sadness.

Patient X feels more comfortable to identify what she goes through and shares this with her family and that family support that she receives in return helps her feel motivated to keep carrying on.

Tips to enhance Emotional Adjustment and Adherence

Emotional adjustment is not a set recipe that all individuals follow to achieve the optimal results, which is adherence to treatment at all costs. Experiences such as hope and **uncertainty** play a pivotal role in an individual's receptiveness to adaptive emotional adjustment. People are different and ways to cope with hope and uncertainty and the impact they have on emotional adjustment and adherence are unique to individuals. However, using our understanding of how **hope** and illness-related **uncertainty** can impact an individual's emotional adjustment and adherence, the following tips are provided to enhance emotional adjustment and adherence:

1. Using open communication to speak about any **uncertainty**, helplessness or despair allows an individual's support system know where they currently are in their processing and can create necessary support.
2. Knowledge is power. Educating oneself about the condition, treatment, as well as the factors such as emotional experiences of hope and uncertainty and how they present and impact emotional adjustment and adherence. This will empower you to be an observer of these experiences instead of a victim to them.
3. Allowing oneself to go through the motions of mixed emotions such as shock, denial, anger, despair, confusion, helplessness, hope, and determination without judging oneself. A non-judgemental awareness of an emotional experience allows an individual the opportunity to experience emotions in a less threatening manner.
4. Relying on a positive outlook can create a sense of hope for an individual and their family. This may mean that an acceptance of adversity is made and a choice to maintain positive coping strategies that encourage acceptance and a positive outlook is maintained.

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Eating correctly for your new kidney

Lila Bruk
Registered Dietician
Lila Bruk & Associates - Registered Dieticians
Johannesburg



After your kidney transplant, you will be much less restricted with respect to the foods you can eat and the amount of fluid you can drink. However, it is still important to monitor your diet after your transplant to ensure that your body recovers well after the operation and to ensure that your new kidney functions well.

- **Keep an eye on your weight**

The cortisone that you need to take after your transplant can lead to weight gain and therefore it is important to avoid high-calorie foods, which may lead to unnecessary weight gain. Therefore, avoid snack foods like crisps, chocolates and biscuits. Also, try to avoid fast foods and deep-fried foods.

- **Watch your carbohydrate intake**

Cortisone can also have a negative effect on your blood sugar, so it is important to limit your intake of sugar and sugary foods, as well as other refined carbohydrates (e.g. white bread) to keep your blood sugar levels more controlled.

- **Be aware of the different kinds of fat**

Cortisone can affect your cholesterol and triglyceride levels, so avoid those foods that are high in saturated and trans fatty acids, which may further raise these levels, such as butter, red meat, commercial pies and biscuits, liver, full cream dairy and brick margarines.

- **Limit salt intake**

Even after your transplant, you may still need to monitor your salt intake. Avoid high sodium foods such as pre-packaged soup mixes, stock powder, tinned foods, breakfast cereals and sauces. Try to instead flavour foods with fresh herbs and spices.



- **Increase your fruit and vegetable intake**

Eat at least 5 to 9 servings of fruits and vegetables per day. One serving of vegetables is 1 cup raw or half a cup cooked. One serving of fruit is a cup of fruit salad, or 1 tennis ball size piece of fruit.

- **Get enough protein**

It is important for your body's recovery to ensure that you eat enough protein after your transplant. Try to include more protein-rich foods such as chicken, meat, fish, eggs, legumes and dairy.

- **Drink enough fluids**

Assuming your new kidney is functioning correctly, you no longer need to restrict your fluid intake. Therefore, it is important to drink enough fluids to make sure that your new kidney stays healthy. Aim for at least 6 to 8 glasses per day and choose water or caffeine-free herbal teas to ensure optimum hydration and rather avoid beverages that contain caffeine.



- **Find out about your potassium needs**

Depending on the medication that you're on after your transplant, you may need to be aware of your potassium intake. Discuss with your doctor whether you need to be conscious of how much potassium you consume in your diet. If you are told to reduce your potassium intake, foods you would need to avoid or limit would include: oranges, potatoes, bananas and avocados.

- **Eat for bone health**

The cortisone can affect your bone health. Therefore, it is very important to eat foods that will improve your bones. Focus on foods high in calcium such as dairy products and fish with edible bones (e.g. pilchards or anchovies). Try to also get about 10 minutes per day of unprotected sun exposure to boost your body's vitamin D levels, which will also assist with bone health.

- **Eat safe food**

The medication after a kidney transplant can lower your immune system. Therefore, it is important to make sure that you only eat food that has been prepared correctly. Avoid raw or undercooked meat, chicken and eggs. Always store foods correctly by refrigerating leftovers as soon as possible to prevent any bacterial overgrowth on the food. Also, ensure that you reheat food until it's fully hot all the way through to make sure that the food is hot enough to kill off any potentially dangerous bacteria.

- **Eat regularly**

You may find that some of the medication you have to take can cause nausea or vomiting. Therefore, you may find it easier if you divide your meals up into smaller meals throughout the day.

- **Keep active**

Regular exercise is important to maintain bone health, keep your weight in check, strengthen your muscles, improve your energy levels and for your overall health and wellbeing. Aim for at least 30 minutes of exercise 3 to 4 times per week. Choose exercise that you enjoy, so that you feel motivated to continue. For example, you could exercise by going dancing, swimming or walking.

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Clauwdet's story

Ms Clauwdet Lok
Paramedic, Director and Founder of
Signs of Life
Richwood, Cape Town

It was Saturday morning, 23 November 2013, when I received the call from my mother informing me that there had been an accident. From the few words she uttered I knew that there was little time to waste. I got out of bed, threw on the nearest attire and started my van – as if in one flowing movement.

While en-route to scene my phone rang again; all I remember hearing was “he’s not breathing”. The sense of urgency overwhelmed my thoughts and planted the accelerator a little deeper into the corner of the floor. Less than 10 minutes from the initial call and we stopped on scene.

I clearly remember grabbing my kit, slamming the door and being led down the side of the building into a narrow alley filled with rubble and debris. That is where I found him; my dad was lying on his back, bleeding, bruised and lifeless. Without hesitation the medic in me took over and the fight for his life began.

Despite our very best efforts I lost my father that day to a heart attack worsened by the fall from the roof and the untrained bystanders that were on the scene from the moment it happened. He was declared Dead on Arrival at hospital.

My dad helped anyone with an outstretched hand while he was alive and wanted to make a difference even after his passing. In order to stay true to him I made the call to the Organ Donor Foundation and we have never looked back.

My family and I received amazing support from all involved in the organ donation process including letters, phone calls and updates. My dad was able to assist 5 burn victims with skin grafts, 2 more with sight from corneal transplants and an additional patient requiring bone for facial reconstruction.

As a tribute to my father and an attempt at creating awareness around the importance of first aid training, as no-one on his emergency scene knew how to help, I started Signs of Life Training Academy (Pty) Ltd. I am a medic by trade but decided to make the shift from being the ONE with the training to the one who trains MANY.



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Signs of Life is now the proud and official sponsor of the ODF Cycle Team and have generously donated funds to make it possible for our cyclists to sport the new ODF Cycle jersey. The Organ Donor Foundation cannot express its gratitude enough and we are looking forward to a long and rewarding relationship with Signs of Life.

20th World Transplant Games 2015 - Mar del Plata, Argentina

Mr Hermann Steyn
Executive Secretary
SATSA



The 20th World Transplant Summer Games took place from 23 to 30 August in Mar del Plata, Argentina. This biennial event lets transplant recipients from across the world compete in various sports and athletics. Team South Africa left on the 20th of August to once again represent our country among 43 other nations.

Our team, which consisted of 46 athletes, did a fantastic job by finishing third overall and raking in a total of 89 medals – 24 bronze, 24 silver and an incredible 41 gold. Great Britain and Northern Ireland took first place, followed by the host country, Argentina.

The purpose of the games is to visibly demonstrate the benefits of successful organ transplantation. It is also a wonderful way to raise public awareness which not only

increases organ donation rates, but also promotes the full rehabilitation and wellbeing of participants.

Executive Secretary and Team Manager of the South African Transplant Sports Association (SATSA), Hermann Steyn said that this event was the perfect platform for athletes to compete at the highest possible level as well as celebrating a second chance at life with more than a thousand people from different nations experiencing the same feeling. At each event he sees reconnecting and forging of friendships characterised by unconditional acceptance.

Hermann also added: "We intend to maintain the high quality of competitiveness and improving on our third position by continuing to maintain the high qualification standards and conducting at least two national training camps after our National Games in 2016 in order to prepare for 2017 World Games in Spain."

