Editorial

This edition of Transplant News focuses less on some of the physical and medical issues around the transplant but more on the psychological as well as problems faced that may arise in daily life after a successful transplant.

We, in the medical fraternity, always emphasise success; of course it is imperative to be positive but one must be aware that despite the best intentions of all parties involved, the outcome may not be successful. That is where patients and indeed doctors may need the psychological help that Tina Sideris so eloquently describes to us.

This is even more acute where the donor is a living donor, closely and emotionally bonded to the recipient. Occasionally the donated organ – usually in this country a kidney – for one or other reason, fails. What a disaster it is for all parties: the donor, having made a major altruistic sacrifice, is awfully disappointed, perhaps even angry. The recipient is also terribly disappointed and has the additional burden that the sacrifice was in his or her cause and all has been to naught. The medical team who bear the responsibility of care are affected too. Extra care and counselling for all concerned is required.

Again we have personal stories of two young girls, Vinolia and Sandra, both requiring double transplants, celebrating life 10 years on. This brings home to all what a wonderful medical advance organ transplantation can be.

Priya Gajjar, a paediatric nephrologist addresses the difficult issue around that stormy period of adolescence, that transition from child to adult.

Paediatric transplant units traditionally provide greater individual succour to both patient and family and when the patient is transferred to an adult unit it is a scary time for them. In the past they were expected to fend for themselves, often with disastrous consequences. This is now well recognised and much more care is given around this difficult time.

Finally, Professor Elna McIntosh, president of the South African Society of Sexual Health Advisors, Educators, Researchers & Therapists, addresses that often ‘difficult’ subject of sexuality. She emphasises that we are all sexual beings and this is just as relevant for the transplant patient and indeed is part of the full rehabilitation to health.
Psychological Issues in Organ Transplantation

Organ transplantation is associated with hope for life extension and improved quality of life. It is, however, a strenuous process that at various stages presents challenges to remaining hopeful. Not least amongst the stressors is the life long commitment to complying with exacting drug treatments, which are absolutely necessary for survival. During the transplant process the primary focus is on the disease and its progression, availability and match of organs, surgery, and preventing dysfunction of the organ. And of course, these are the factors that determine hope.

Nevertheless, the illness experience and transplantation confront patients with a complex array of factors that constitute a significant strain on psychological wellbeing. Importantly, research reveals a strong association between physiological and psychological wellbeing, and that psychological factors mediate compliance with treatment.

At various stages of the transplant process severe stress factors include:

Pre-transplant stressors:
- Confronting life-threatening disease
- Knowledge of the discrepancy between patient’s needing transplant and availability of organs
- Disease progression and reduction in functional capacity whilst on the waiting list
- Changes in personal and work roles with increasing dependency on others
- Financial considerations

Post-transplant stressors:
- Stressful ICU environment and medication which can result in severe disorientation and de-personalisation
- Post ICU fears regarding outcomes and graft dysfunction
- Long-term adjustment to immunosuppressant medication
- Ongoing worry about rejection and infections
- Adjustment to changes in lifestyle and roles
- Re-entering the work environment
- Financial stress

Pre- and post-transplant these stressors are risk factors for:
- Anxiety
- Depression
- Post traumatic stress
- Adjustment disorder

Studies suggest prevalence rates for depression between 4% and 58% across different organ transplant patients; for anxiety between 3% and 33%.

Physiological and psycho social wellbeing are firmly linked

In the light of the precedence of medical concerns, it is understandable that patients want to downplay or deny their emotions, neglect attending to how they cope with and defend against stress, avoid examining beliefs and attitudes towards medication, and shelve thinking about lifestyle.

However research shows that:
- Even after controlling for medical complications, ongoing anxiety is associated with poor post-operative recovery and increase in physical complaints
- Depression leads to loss of motivation, hopelessness, and poor treatment compliance
- Post traumatic stress poses increased risk for physical complications
- Coping strategies influence emotional responses, which in turn mediate treatment compliance and health outcomes
- Realistic expectations about the emotional strain that is involved in transplantation mediate positive health outcomes

In as much as patients scrutinise their physiological wellbeing it is important to monitor psychological reactions to the disease and treatment and to seek professional help pre- and post-transplant.

Factors that mediate psychological wellbeing

Self observation and awareness: On initial diagnosis denial can be an adaptive defence to protect against overwhelming anxiety. Longer-term, acceptance of the disease and changes in functioning and acknowledgement of fears, provide for improved psychosocial adjustment to strenuous treatment.

Disclosure: In contrast to avoidance, communicating with sympathetic others, sustaining intimate and social attachments, maintains hope and a positive orientation to life.

Social support: Accessing and using social support beyond the primary care-giver, to include seeking professional support improves adherence and compliance, with the proviso that support should not enable dependency.

Active coping strategies: Active interest in information on the disease and on treatment, and belief in own capacity to impact on health - within reasonable limits, improves sense of self-efficacy, autonomy and control, leading to improved psychological wellbeing and adherence to post transplant lifestyle requirements including diet, exercises and abstinence from substances

Beliefs about medication: Negative beliefs about medication are associated with decreasing compliance over time. Being in possession of accurate information on the absolute necessity of medication, and pragmatic acceptance of the risks and side effects improve compliance.

Attitudes toward the organ and donor: Transplant patients are expected to accept the organ as their own immediately. It is however, reasonable to expect that there will be worrisome thoughts about the donor and donated organ, and that reconfiguring one’s identity as an organ recipient is a process that takes time.
very day was an emotional roller coaster, lived in a bubble of expectation and anxiety. But in one phone call their lives changed forever because someone somewhere agreed to be an organ donor.

The devastating prognosis - two families faced burying a child
As World Health Day took place on 7 April this year, the Organ Donor Foundation celebrated life with two young women who had never met but who share a life-long common bond. Ten years ago, in the face of a devastating doctor’s prognosis, their families were preparing themselves to bury a child. Today they are young, healthy and ambitious, living full lives just like any of their peers.

On the face of it, Sandi Wares and Vinolia Naidoo are no different from the average student in Durban or Cape Town. Sandi, in her final year of an animation degree, enjoys spending time with her two sisters and sailing with her dad. Vinolia is a third year law student who firmly believes that every challenge in life is an opportunity to strengthen our resolve.

Rewind the clock by ten years and the picture is very different.

Their stories have many painful parallels. The pain their parents felt as their critically ill daughters were diagnosed with chronic diseases. The emergency trips to hospital. Days and nights on dialysis and in ICU. The chance that their lives would be cut unnecessarily and painfully short.

The phone call that brought hope and changed their lives
The only solution was for each young girl to receive a liver and a kidney transplant. The families put their lives on hold, waiting for the call. Every day was an emotional roller coaster, lived in a bubble of expectation and anxiety.

Then one day, one phone call changed their lives forever. Their doctors called to let them know that matching organs had been found and were ready to be transplanted. Sandi and Vinolia each received simultaneous kidney and liver transplants from anonymous donors.

Both of these young women are alive today, living healthy, normal lives because two other people agreed to be organ donors.

Vinolia says: “Before the transplant I was connected to a dialysis machine for ten hours a day. But on that day in 2002 I received the gift of life. I learned then that when love and skill work together, expect a masterpiece.”

There are currently 3 500 people awaiting transplants across South Africa and the Organ Donor Foundation wishes to encourage people across the country to register as an organ donor. Linda Peel, Executive Director of the Organ Donor Foundation explains: “When someone receives an organ from a donor, their lives change immeasurably. Being able to live long, healthy lives they can become economically active and support their families. They can contribute to the general health and wellbeing of their families, communities and society as a whole. On World Health Day, we celebrate that fact. As an organ donor, it’s possible for everyone to help to build a healthy world.”

For more information, visit the Organ Donor Foundation website at www.odf.org.za, or phone their toll free number on: 0800 22 66 11.
Being an adolescent with a chronic disease
Adolescence is a particularly difficult time because of:
• the need to find identity
• pressures from peers
• pre-occupation with appearance
• a sense of invincibility

Added to this, a burden of a serious chronic disease leads to:
• overprotection from parents
• constant authority from professionals
• a learned dependency and delay in maturation process

Frequent hospitalisations result in:
• school absenteeism
• missed educational opportunities
• less likelihood of finding a job
• a feeling of failure

This can be exacerbated by the inherent social pressures of parental unemployment and poverty, diverse cultural beliefs and language barriers.

Transitioning from paediatric care to adult services in adolescence
Parents who are the key role players in the care of these children have:
• a close bond with the treating paediatrician
• involvement with the medical team in the decision-making

The adult physician might find the parents’ involvement as intrusive. The parents know their children well and are acutely aware of their children’s shortcomings and remain concerned about their ability to cope in the adult service. As a parent of a teenager with a chronic condition, one needs to promote the child’s independence and sense of responsibility. The paediatricians must also ensure that certain milestones are reached prior to the transfer.

Paediatric vs Adult care services
Having cared for the patient and the family for a long time, the paediatrician may also be reluctant to move your child onto adult care services. He/she may be:
• anxious of letting go
• fearful of suboptimal care and lack of continuity
• wary of adult care model
• concerned about poor knowledge of resources available
• distrusting and transfer his/her “mistrust” onto the patient and/or patient’s parents

Some advantages of being treated by the paediatric unit will be lost when moving to the care of an adult care unit.

The paediatric unit:
• has favourable staff-to-patient ratios
• runs a family orientated service
• has time for open communication and sharing of information

The adult unit:
• deals with a higher patient load
• runs at a faster pace
• has a rapid turnover of patients and less time to spend on each patient
• provides less time to counsel and to explore other important issues related to being an adolescent

Furthermore, a physician treating a new adolescent patient with a chronic illness has the challenges of dealing with:
• adolescents in different stages of their development and of
• unfamiliar disease processes such as congenital disorders and rare genetic disorders not usually encountered in adults

With these concerns and reservations in mind, we should aim to cultivate a partnership of trust between the patient, patient’s family and all healthcare givers concerned to encourage learning from each other.

Adolescence and non-adherence
Adolescent transplant patients and young adults are a particularly high-risk group for non-compliance and graft loss because:
• of their tendency of risk-taking behaviour
• the strict regimens leave them with little room for error
• the medication itself may have negative cosmetic side-effects
• their feelings of anger, depression and denial if not effectively managed, may be displaced onto the chronic disease

These risk-factors need to be addressed as non-adherence in transplant recipients can lead to organ dysfunction and loss of life. Thus, open communication and supportive co-operation are critical to help the young transplant patient maintain optimum control and good health.
The Ready Steady Go team (local transition service) - What we have found useful:

- Prepare early: As early as 10 to 14 yrs of age with the help of psychosocial services e.g. counsellor
- The timing of transition should be based on the adolescent’s
  - emotional maturity,
  - disease stability and
  - readiness (see Important milestones to achieve before transfer)
- Do not consider a change/transfer in the midst of a major medical or psychological crisis
- Participation in adolescent workshops that address:
  - the difficulties of having a chronic illness and
  - fears and anxieties of transitioning
- Celebrate transition with a “graduation lunch and certificates”
- Arrange a guided tour of the hospital to help the patient become familiarised and to ease anxiety
- Encourage formation of a buddy system where an older adolescent teams up with a younger one.
- Provide a care card to access services after hours and in case of emergencies.
- Provide support groups prior to the clinics:
  **For the adolescents**
  - allowing space to deal with day-to day changes
  - maintain consistency of care and compliance
  **For the parents**
  - should also make use of counselling and support groups to help “let go”

Management strategies to address non-compliance

- Build trusting open relations
- Be informed and educated regarding treatment regimens with the use of booklets, fridge charts, pamphlets, etc.
- Help improve compliance by
  - simplifying the regimen
  - using medication with longer half-life (ask your doctor for options)
  - tailoring the regimen to suit the patient’s lifestyle
  - use dose containers to avoid errors and missed doses
  - use alarms or sms alerts as reminders
- **Availability of a structured clinical and social network support**
  - the adolescent patient should be allowed to visit frequently and should feel free to raise any questions
  - availability of a peer support group

Important milestones to achieve before transfer

- The adolescent must:
  - have an understanding of their disease process and importance of lifelong follow-up and medication
  - have an awareness of the implications of the transplant/disease on their health particularly infection and cancer risk
  - have an understanding of the impact on sexuality and risks to pregnancy
  - have a sense of responsibility for their own healthcare
  - know their medication and have the ability to memorise their prescriptions accurately
  - be able to make and keep appointments
  - independently communicate their health needs and know when and how to seek urgent medical attention
  - have the capacity to provide care for themselves
Sexuality after transplant

Sexuality can sometimes be affected by a serious illness, such as an organ transplant and by its treatment. By sexuality we mean the feelings we have about ourselves as sexual beings, the ways in which we choose to express these feelings with ourselves and others, and the physical capability each of us has to give and experience sexual pleasure.

Sexuality can be expressed in many ways - how we dress, move and speak, as well as by kissing, touching, masturbation and intercourse. Anxieties about survival, family, finances and changes in body image and activity tolerance can place a strain on the expression of sexuality and create concerns about sexual desirability.

If you were comfortable with and enjoyed your sexuality prior to your illness, the chances are excellent that you will be able to keep or regain a healthy sexual self-image despite the changes brought about by transplantation. Many people who had a transplant or who are the partners of persons who required a transplant may not experience any change in sexual feelings or behaviour. Others may find that increased closeness and communication resulting from the experience of illness enhances their sexuality. Still others may never have considered sexuality to be of great importance in their lives, or may consider it less important now than previously.

If, however, you are experiencing some changes or stresses in your sexuality because of your transplant or its treatment, I would like to help you explore ideas for dealing with these changes. I do not intend to present a course in sex counselling, nor a list of how to’s about sexual functioning. Nor do I intend to suggest that everyone with a transplant will have sexual problems. Sexual problems frequently arise not so much from changes imposed by medical conditions or their treatment per se, but from how we feel about and deal with those changes.

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Ways to get more comfortable discussing sexuality with your partner.

Our ideas about the “right way” to be sexual come largely from myths or expectations we grew up with that may hinder expression of our sexuality. Let’s take a look at some of the more common myths:

Common myths about sexuality
- Sex is only for the young and able-bodied
- Sex means intercourse
- The goal of sexual activity is orgasm
- Sexual performance equals love
- Sexual activity is natural and spontaneous
- Masturbation is harmful

The sexual response cycle

Understanding how your body changes when sexually aroused can help people understand the particular conditions needed to enjoy sexual activity. The more aware we are of what is right for us, the greater are our chances of enjoying sexual pleasure. Most of us have learned one way of obtaining sexual satisfaction or orgasm - through various kinds of genital stimulation such as masturbation, intercourse, and oral or manual stimulation. Many people, however, are able to experience sexual excitement, even orgasm, through stimulation of other sensitive body areas. Since it is the brain, rather than the genitals, that interprets and experiences this stimulation as pleasurable, we could say that the brain is the real sex organ. This means that we do not have to depend on our genitals for our sexuality. Our options for sexual pleasure are as varied as our imaginations.

Many people with serious illnesses find that the circumstances they need to enjoy their sexuality have been altered in some way because of the illness and its treatment. Under the stress of worrying about the future, they may consider it less important now than previously.

"We are all sexual beings." This simple statement makes the important point that sexuality is part of who we are, not just what we do. Sexuality is expressed in many ways - how we dress, how we talk, how we work and how we play. Furthermore, each of us is uniquely sexual in the sense that we each choose whether or not to be actively sexual in what ways, how often, and with whom. If sexuality were something people could easily discuss, we would no doubt see that the importance of sexuality varies tremendously from person to person.

Remember, you are the expert on your own sexuality. I hope that the material presented here will validate your sexual concerns and stimulate your thinking about how best to handle them. If you do not find your individual concerns or questions discussed as thoroughly as you might like, please consult your Health Care practitioner to refer you to a sex therapist or a Sexologist in your area or see the list of Self Help books that I have suggested.
and worry of a life-threatening illness, expression of sexuality frequently takes a back seat. It is difficult to feel sexual when you are fighting to survive, are in pain, or constantly tired. Treatment for an organ transplant may involve lengthy hospitalisations and separations from those you love. Hospitals or convalescent facilities usually do not provide much privacy and hence there may be little opportunity for sexual expression.

During illness, the control you usually experience over your body may be lost, and you may feel inadequate and helpless. Serious illness may change the way you experience your body, or actually change the way you look, through surgery, scarring, weight loss, or other events. These changes may create painful anxiety about whether you will be able to function in your accustomed social, sexual and career roles or about what people will think of you. This anxiety, the depression and fatigue that may accompany it and the numerous other worries that can occur with serious illness understandably make sexuality assume less importance.

Once the immediate crisis of serious illness has passed, however, sexual feelings and how to express them may become important to you. Feeling anxious about resuming sexual activity is normal and natural. It is easy to get out of practice when you are away from any activity. You may have questions about whether sexual activity will hurt you in any way or if you will be able to experience sexual pleasure. Your partner may share the same worries and may be especially concerned about tiring you out or causing you pain.

Although healthcare personnel are now more aware of sexual concerns, many people continue to receive little or no information about sexuality during their treatment or recovery from illness. You may in fact have no real opportunity to ask important questions. If sexuality has not been discussed with you or if your questions have been avoided, you may feel that your worries and questions are foolish, unimportant, or perhaps inappropriate. Don’t let these feelings prevent you from seeking answers. Ask your doctor, nurse, social worker, or other staff person with whom you feel comfortable. They should be willing to listen to your questions and either answer them or refer you to someone who can. Help is available. Some medical centres offer sexual counselling specifically for people with medical illness or physical disability. Your doctor or social worker will know if these resources are available near you.

Body Image

Treatment may directly affect some people’s physical ability to get erections, ejaculate, have intercourse, or orgasm. The same treatment for another person may result in little or no change in sexual functioning. This means it is quite often impossible to predict the effects of treatment for any one individual. Sexual problems that may appear to be physical results of treatment may in fact be due to anxiety and concern about body image and sexual functioning. Discussing potential problems and possible solutions with your doctor or other members of the health care team prior to treatment will reduce worry and reassure you that, if problems do occur, there are ways of handling them. Since in most situations there are no totally reliable means of sorting out physical from emotional causes of sexual problems, your exploration and experimentation about what you can do is most important. Your diagnosis does not dictate what is possible for you sexually.

Some medical centres offer sexual counselling specifically for people with medical illness or physical disability.

Energy level

Life after organ transplant treatment may be exhausting. Fatigue, depression and generally feeling sick are common. Treatments may in themselves also create unpleasant and tiring side effects. The amount of energy available to you for activities of living, including sexual activities, may vary from day to day or week to week. Some people learn to cope with these variations in energy level by planning their activities to coincide with times of the day they feel best. If you are experiencing some of these difficulties, being sexually active may not always be important to you. But for times when it is, planning to have sex when you feel least tired may be helpful.

Painful Intercourse

One problem that may result for women after treatment is painful intercourse. If you find that intercourse has become painful for you, it is important to visit your physician or gynaecologist for an examination to determine the cause of the problem. It may be related to surgery, side effects of medication, or be the result of a simple problem, such as an infection, e.g. Bacterial vaginosis, or Thrush. If the cause is insufficient lubrication, suggestions include the use of artificial lubricants such as Astroglide, Gyno-Moistrin, or KY Jelly; vaginal moisturizers such as Replens; and vaginal and vulvar application of oestrogen creams.

Erection

For men who have trouble getting and maintaining erections and who suspect that this may be due to treatment, we would suggest the following: Since some drugs can temporarily interfere with the ability to have erections, you may want to ask your physician about any possible side effects from drugs you are taking. If you get an erection with masturbation or you wake up in the middle of the night or in the morning with one, you will know that anxiety or “trying too hard,” rather than a physical problem, is what keeps you from having erections.

In trying to deal with erection problems it is important to explore the sensations in and around your penis. Learning about what feels good to you is valuable in showing your partner what pleases you most.

The more options you have for sexual expression, the less pressure there is on having erections; this in turn makes it more likely that they will occur.

If erections have not returned and you feel that this is important to you and your partner, you may consider asking your doctor to refer you to a sex therapist for brief counselling. If after counselling you are still not getting erections,
your counsellor may refer you to a urologist, who, together with you and your counsellor, can make a careful assessment of whether or not one of the following medical treatments would suit your particular needs and those of your partner:

- Viagra (Sildenafil);
- Cialis (Tadalafil);
- Levitra (Vardenafil);
- Antidepressant medication;
- Intraurethral delivery of medication;
- External penile vacuum device;
- Intracorporeal penile injections;
- Penile implant surgery;

**Orgasm**

After a serious illness, an interruption in your usual ability to experience sexual pleasure can be perfectly natural. For some women, this interruption may make having orgasms more difficult. If this is a problem for you, learning to re-explore pleasurable body sensations may be helpful. Doing this at a time when you can be alone and are not distracted by having to please or perform for your partner is important.

**Summary**

- Survival overshadows sexuality
- Expect the unexpected
- Give yourself time
- Communication is all-important
- Take the pressure off intercourse
- Don’t let your diagnosis dictate what you can do sexually
- You are loved for your total worth, not just for the appearance of your body
- You don’t have to do it all yourself

**Commonly used medications that may impair sexual function**

- Benzodiazepines
- ß-Blockers
- Calcium-channel blockers
- Cimetidine
- Digoxin
- Lipid-lowering agents
- Lithium
- Monoamine oxidase inhibitors
- Neurotoxic cancer chemotherapies
- Oestrogens
- Opiates, including synthetic opiates
- Phenytoin
- Progesterones
- Thiazide diuretics
- Tricyclic antidepressants
- Selective serotonin reuptake inhibitors

**Suggested Reading**

- *The Book of Love* by Dr Laura Berman, 2010. Achieve your best life together with this ultimate sex and relationship guide for couples, introducing sensual new positions and techniques with reassuring advice on strengthening emotional bonds.
- *The New Male Sexuality* by Bernie Zilbergeld. Boston: Bantam, 1992. A common-sense, practical, and sane antidote to media pressures on males to be sexual superstars. Excellent discussion of the fantasy model of sex and myths of male sexuality, the importance of an individual’s conditions for good sex, and specific self-help chapters dealing with common male sexual problems.

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**Cape Kidney Association**

**World Kidney Day ‘Sunset 5km Walk’**

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To celebrate World Kidney Day on the 5th March, members and families of the Cape Kidney Association took part in a “Sunset 5km Walk”. Thanks to all who turned out and took part in the enjoyable event to create awareness.