

# The Liver Lifeline

## Presidents Note

-By Mark Rosser

Welcome to the November issue of the Liver Lifeline. I would like to thank all of the Executive Committee and members for all of the support they have shown over the last four years, with a special thanks to the members who without fail man all of the events the group holds.

Having said that it is with great pride and pleasure that I announce the re-election of the Executive Committee, the members are;  
President – Mark Rosser  
Vice President – Doreen Cheong  
Treasurer – Jim McKinlay  
Secretary – Jennifer Loupis  
Minutes Secretary – Margaret McKinlay

This year has proven to be very successful and we have had the honour of;

- Being able to help a number of patients
- Purchase equipment for the Surgeons
- Purchase an Encyclopaedia for the Physicians
- Being an integral part n the launch and celebrations of the National Institute of Transplantation.

Our bank balance is looking very healthy, thanks to the excellent funds being raised through the stall, and donations.

The launch and celebrations of the National Institute of Transplantation was flawless with almost 600 people attending.

Our website: [www.liversupportgroup.org](http://www.liversupportgroup.org) is now fully operational and is being viewed by people all over the world.

On behalf of the Liver Support Group I would like to wish you all a very Merry Christmas and a Happy New Year.



## Blood Glucose Levels (BGL's) after Liver Transplantation

- Helen Vidot

- This information is offered as general advice. It is not meant to replace individual dietary advice you might receive from your dietitian.
- Over the two to three months after transplantation there will be changes in your nutritional needs. These should be worked through with your dietitian.
- If you still have diabetes twelve months after transplantation, you should seek additional help through your local dietitian or the diabetes centre about long-term diabetes management.

### Type 2 diabetes (diabetes mellitus)

- The main feature of diabetes mellitus is high blood glucose levels. (BGL)
- This is usually because either the pancreas not producing enough insulin or the insulin that you make is not working as efficiently as normal.
- Eighty five to ninety percent of all cases are Type 2 diabetes.

- A family history of diabetes, lifestyle factors and age > 40 years are risks factors for the development of Type 2 diabetes.
- People who have diabetes have a greater risk of having high blood pressure, high bloods fats and are more likely to be overweight or obese.

### **Incidence of diabetes post liver transplant**

- Some anti-rejection medications used after transplantation make it difficult for the insulin that the pancreas makes to work.
- **Most** patients in hospital after liver transplantation will have high BGL's
- Most people will need insulin injections at this time to keep BGL's within the normal limits.
- Some people will have normal blood glucose levels when they leave hospital.
- **Most** people will need insulin injections or tablets to control their blood glucose levels after they leave hospital for some time.
- As the anti-rejection drugs are reduced BGL's fall and less insulin or tablets are needed to keep BSL's within the normal range.
- **Seventy five to eighty percent of people will not need** insulin or tablets to control their BGL's by twelve months after transplant.

### **Overweight and obesity**

- Around 70% of people are overweight or obese at twelve months after their transplant.
- There is a strong association between overweight/obesity and the development of Type 2 diabetes and non alcoholic fatty liver disease.

## Eating Pattern

- The foods and the times you eat can change your blood glucose levels. Here are a few basic rules to control your BGL's:
- Eat regularly - Do not miss meals - Include snacks between meals.
- If you are unwell and unable to eat, try an extra supplement drink to keep you going - if you continue to have difficulty eating contact the dietician in clinic.
- Space the carbohydrate or starchy foods around the time your anti-rejection drugs are peaking. You should try to eat less starchy foods at lunch and afternoon tea.

## What to eat

- Eat a meal that includes protein rich food, a starchy food and vegetables and/or fruit - Snacks between meals should contain a protein rich food with a starchy food.
- As you start to regain weight, choose foods that are lower in fat, Reduce your serving sizes at meal times, Stop snacking between meals
- Stop using the dietary supplements and change the type of fat you eat to the "heart healthy" fats i.e. canola, olive or polyunsaturated oils and spreads
- If you are on insulin you will need to adjust your insulin when dietary changes are made

## Carbohydrate Foods or Starchy Foods

Carbohydrate includes all starches, all types of natural and refined sugars. They are all digested, absorbed and converted into glucose.

Carbohydrates are the best energy source for your body.

## All Carbohydrate Raises Blood Glucose Levels

- Carbohydrates are broken down and absorbed at different rates
- The **Glycaemic Index (GI)** describes how a carbohydrate containing food can affect BSL's.
- Low GI foods raise blood glucose levels slower than High GI foods. Including at least three low GI foods throughout the day can help with BGL control.

## Carbohydrate rich foods include:

- **All breads**  
Dense wholegrain breads such as Burgen Oat Bran and Honey loaf®, Burgen Soy and Linseed loaf®, PerforMAX®, Ploughmans Wholegrain® and Multigrain 9-grain® have a low GI.
- **Sourdough breads** have a low GI.
- **All breakfast cereals** including high fibre breakfast cereals  
Rolled oats, All-bran®, Mini Wheats®, (whole wheat) and untoasted muesli have a low GI.
- **All pasta and noodles** - All pasta and noodles, except rice noodles, have a low GI.
- **All rice** - Basmati, Doongara, Mahatma Premium Classic®, have a low GI.
- **All cereals** - Oats and barley have a low GI.
- **All legumes** - Baked beans, kidney beans, chickpeas, lentils and three-bean mix all have a low GI.
- **All fruit and fruit juices** - Apples, oranges, stone fruits (apricots, cherries, nectarines, peaches, plums) and bananas have a low GI.
- **Milk products or dairy alternatives** - Milk, soy drink (calcium fortified), custard, yoghurt and ice cream have a low GI.

- **Some vegetables contain starch.**  
These include potato, sweet potato, yam, corn and peas.
- **Some vegetables** like peas, corn and sweet potato and yam have a low GI.

### **Protein rich foods include:**

- Lean meats - beef, lamb, pork.  
**Avoid** all raw meats and smoked meats
- Poultry - without skin.
- All seafood - avoid all raw and smoked seafood, raw oysters in particular.
- Eggs - must be cooked, not runny.
- Soy products such as tofu.
- Legumes such as dried beans and lentils.
- Cheeses, yoghurt, milk. Avoid cheeses that have been identified as possible sources of Listeria.

### **Supplements**

- You should only continue to use supplements on your dietician's or doctor's advice.
- At home supplements should not be used in the afternoon between lunch and dinner (tea), unless you are told to do so by your dietitian.
- As you approach your individual ideal weight you will need to stop using supplements. If not, using supplements at this stage you may gain weight quickly. Making it more difficult to control your BGL's

### **Activity**

- Regular physical activity can help to control your BGL's.
- Increasing your activity is important for a number of reasons:
  - Reduce your insulin requirements.
  - Make it easier to control your weight

- Help you feel better - Increase your physical fitness/ strength.
- Increase your muscle bulk, which will result in reduced insulin requirements.
- Some people find using a pedometer useful to monitor their activity. It is even better if you keep a written record of your day's activity to help motivate you to increase your activity.

### **FROM A PARTNER'S PERSPECTIVE**

**- Margaret McKinlay**

Previously the newsletter has had stories from people who have had transplants but I would like to tell my story about my husband's liver transplant.

Jim had been sick for some time and had been treated by a local gastroenterologist, he had had treatment for oesophageal varices and various other problems when it was decided that he needed more specialised treatment and a possible transplant and he was sent to the A W Morrow Clinic. He attended the Clinic for some time before one visit when Prof. McCaughan said Jim should be put on the waiting list for a transplant (we thought he was already on the waiting list). My comment to this was to ask what the alternative was, it is pretty confronting to be told "There is no alternative; he'll be dead within a year". We then met the Assessment Panel, which was quite daunting, for them to assess Jim and evidently he passed because shortly after I got the 'phone call we were both looking forward to and dreading – that they had a liver for Jim and to come into RPA straight away.

Two of our sons came with us; the third had the flu and did not come. Jim was wrapped in blankets and a couple of hours later was taken to the operating theatre. It may seem strange but neither Jim nor I ever considered that he may not come through the operation, we both said "I'll see you later" when he went into the theatre. I got a message the next afternoon from Dr Verran that the operation was a success and we could see him in Intensive Care the next day.

Seeing him in Intensive Care was a shock, he seemed frail and it was only then that the enormity of the operation struck me. He was only in Intensive Care for a few days before going to the Transplant Ward. Jim seemed to be progressing well when he had to go back into the operating theatre to have a large blood clot removed. Back into Intensive Care for a few more days then back to the Ward.

Jim's recovery was very good considering that he was in his 60's. He had a few things that upset him, especially hallucinations – he would have great conversations with people who were not there; in his imagination he rebuilt a boat, arguing about how things should be done, only to open his eyes and realise he only had me there. We were lucky in that I had stopped work 3 months before his transplant so I was able to visit every day and take food which he enjoyed as he had trouble eating. He lost an enormous amount of weight and little things irrationally irritated him. One particular day he was being difficult and Margaret Gleeson found me in tears outside his room, she gave me good advice – don't put up with any nonsense, tell him if he keeps this up you will go home and he will be on his own. It was good advice as he liked me being there. During the later part of Jim's stay in hospital our 2 year old grand-daughter was near death from meningococcal and that added to our stress. Fortunately she pulled through but it was an anxious time for all.

Six weeks after the operation Jim came home and apart from a few relatively minor incidents has progressed wonderfully. He is extremely conscious of the importance of taking his medications, eating well and not putting himself at risk. We recently celebrated his 6<sup>th</sup> Transplant Anniversary and life is very good.

I believe partners play an extremely important part in a transplant patient's recovery but partners also have to remember to look after themselves. It is very easy to allow your partner to get away with things

that you would not put up with if they were not sick, but don't do that, make them understand that life is difficult for you too and it should be a partnership in the true sense of the word.

## **An Interview with a Long Time Recipient -Doreen Cheong & Charyl Walsh**

We thought it would be informative and inspirational to have a fellow liver transplant recipient give us her story on what has happened in their life post-transplant. Charyl Walsh had a liver transplant in March 1990 and is a great example of the quality of life one can achieve if the motivation and approach to life is healthy and positive. These were Charyl's responses to questions put to her by Doreen Cheong.

### ***What were your feelings and reactions when you were told that you had a liver disease that was life-threatening with the prognosis being that you would need a liver transplant or come to an untimely end?***

The first time that I was told that I may need a Liver Transplant I just laughed and said yeah sure, went home and didn't think about it anymore.

But as time went on and things did not improve and they started me on Steroids, I started to feel there was a chance it was really going to happen. I am a very determined person and nobody was going to give me a transplant without me first trying everything possible to heal myself, so I immediately became Macrobiotic and tried to cleanse my body, I did this for about a year, I was definitely healthier, but my liver was far too damaged to be healed by this method.

I then knew I had no choice and put my life and wellbeing in the hands of the experts, and having tried all I could to heal myself was more than happy to do so.

### ***What was the reaction of your family?***

My family like myself were shocked but were so supportive and I knew they would do whatever it took to help me recover.

### ***How essential was the role of your primary carer, during and post-transplant?***

The most important thing during and post transplant was that my daughter who was 5 at the time was well looked after, and if I did not have to worry about her, I was going to recover a lot quicker. She was in the hands of grandparents and living at their house until I had time to come home and become rested. Then after a month, she came home and I was in a much healthier state to look after her.

My husband was a great support and you need someone who is going to be there for you, but also allow you to get on with your life, and get back to normal life again.

***Tell us about how you felt following your initial and follow-up visits to the Liver Transplant Clinic at RPA, prior to the transplant.***

Once I had allowed myself to accept that I was going to have a transplant, I was transferred from Westmead to RPA which was the best thing that happened to me. At Westmead, they did not give the same care as RPA. When I arrived at RPA and spoke to Dr. McCaughan, I felt so relieved. He took me off all the medication I was on at Westmead and I felt so much better. You just feel better if you feel confident in the people who are looking after you. I actually was in hospital most of the time up until the transplant, as I had a lot of fluid and needed 5 litres twice a week to be drained off my stomach and it was very uncomfortable to get around.

***How did you handle the waiting period once you knew that you were on the "list"?***

Once I was on the list, I just basically got on with my life the best I could, waiting for the call. It all seems a little like it's not really happening, until you get the call and then you know it is for real, and you go into shock, and it is a scary time as it is the unknown.

***How did you manage the post-operation period and the rejection management aspects?***

After transplant, you have all sorts of instructions about rejection, what you should and should not do.

I stayed away from people with colds, chicken pox etc, the obvious things. For a while there with all the instructions about what I should and shouldn't do I wondered if I would ever live a normal life again.

I decided that within reason I would get on with life as normal, but I always was aware of the things I had to consider re rejection. I honestly thought that I should just get on with life, avoid the things that could affect me the best I could, but I did not let it rule my life.

***How long was it before you felt physically and emotionally well enough to resume your pre-diagnosis activities?***

I believed that the most important thing after transplant was to rest the body for at least a year, even though, many people felt they had something to prove and raced back to work etc. Even though there was an urge to resume work and normal activities, I thought the body needed a total rest, something I had never done before, a reason why I feel I was so rundown and why I ended up with a chronic auto-immune disease. So I thought this time, I will take my time and fully recover, giving myself a full year to recover.

Many of my friends, I met in Hospital, who rushed back to work had set backs and I had no intentions of this happening to me.

And to this date (touch wood) I have a very fulfilling life. I feel I was sensible and reaped the rewards.

***What motivated you to participate in the Transplant Games?***

I have always been a very sporty person, playing squash, netball etc. and when the World Transplant Games were in Australia, I could not let this opportunity go by without participating, probably my only opportunity to win any medals. I love competing, and it also was a way of feeling like I was fully back to normal life.

The reason I participated in the Australian Games, was the fact that my niece had had a double lung transplant and I promised her if she

recovered by the time the Games were on I would compete with her. That was a very satisfying thing to do, and we both enjoyed the whole experience.

***What has been the best experience/learning from pursuing such a busy and active life (post-transplant) and what tips can you pass on to fellow liver transplant recipients?***

Personally, it is such a cliché but life is different post transplant, you do look at life differently.

Life changes, you have been given another chance.

Personally, I decided that I needed to be healthy, fit and enjoy life. So consequently, I try to eat well, a diet that is very low in salt, due to steroids, which builds up fluid and adds to weight problems which people experience from being on steroids. I don't have that problem, but that is due to watching what I eat, regular exercise and generally enjoying life.

Of course I have my ups and downs, but I also have the attitude that you need to get on with life, why waste what you have been given.

***Tips***

Look after yourself  
Stay fit and healthy (that means eating healthily and doing exercise)  
Make the most of your new life and enjoy.

***Every transplant recipient deals with their life in their individual way but what practical advice can you give from the perspective of 16+ years post-transplant?***

I have really already answered this in Question 9.

I just don't seem to be able to just accept things these days, I seem to have to make the most of the moment,

With work, I am a celebrant and enjoy that immensely, it's fulfilling and

enhances my life as I feel like I am doing something special for that couple at the time. I have very special friends (and I seem to choose my friends differently). I want friends to make me laugh and I feel that friends should enhance your life. I have had some of my friends for 40 odd years and then there are my new friends, that are there for a reason which probably is to help me enjoy this next chapter, and I look forward to that. I am 53 and it's a great time of life, your kids have grown up, you have more time for you and you need to enjoy that time and I intend to.

***Can you briefly speak about your journey (post-transplant) in respect of your work and recreational commitments?***

After transplant I had a year off, so that I was totally recovered and ready to resume work.

I became a sales rep with Dulux Australia in 1991, and I am still a rep having now been with Dulux for 16 years. (part-time)

In 1995 I finally became a Civil Marriage Celebrant which I had applied for 13 years previously.

I just felt like life was coming together when I was notified that I was a celebrant. I have loved it ever since.

I have played competition squash for approximately 30 years with obviously a few breaks in between.

This season is the first season I have not played, deciding to do Pilates and Yoga instead. I felt these two were good for both body and soul, and I feel in your fifties, that's what we need more, than trying to prove something on the squash court, especially when I was finding it hard to find time to practise.

In my position as a sales rep, I do a lot of walking, making it also an exercise, by walking up stairs and escalators. Every little bit helps.

### ***And, finally, what is your motto on life?***

I feel like life is full of challenges and it is about how you approach each challenge, and how you deal with it, that basically moulds your life.

My motto would be to never take anything for granted, and in the end, it is you and only you, and how you handle life's challenges, that will decide how successful and satisfying your life is.

### **The Liver Support Christmas Lunch**

This year's lunch will be held at

**Venue:** The Mercure Hotel Sydney,

**Date:** 16<sup>th</sup> November 2006

**Time:** 12pm Meeting for Lunch  
At 12.30pm until 2.30pm

Lunch will be a Buffet with a wide variety of food to suit everybody's needs.

**Payment:** The cost of the lunch is \$40 per person. Please forward payment to:

Mark Rosser

4 Hickory St

Woonona NSW 2517

**NB: Payment needs to be received no later than the 30<sup>th</sup> November 2006.**

Please make cheques payable to The Liver Support Group. The menu can be viewed on

#### ***Stall Donations***

*"To ensure the continued success of the stall, please assist us by donating your old books, toys, baby clothes. If any body is able to knit or crochet babies clothes, please assist, these articles are the biggest sellers on the stall.*

*Thank You"*

Articles may be left with any of our wonderful Clinical Sisters at the:

[www.liversupportgroup.org](http://www.liversupportgroup.org) – Email: [President@liversupportgroup.org](mailto:President@liversupportgroup.org) Ph: 0418 231 824

A.W. Morrow Clinic  
Postal - 4 Hickory St Woonona NSW 2517 – Ph: 0418231824

Level 9

Royal Prince Alfred  
Hospital.

our website [www.liversupportgroup.org](http://www.liversupportgroup.org) and will be on display at the A.W. Morrow Clinic on Level 9 RPAH.

***In order to conserve the Liver Support Groups funds and to help the environment, please let us know if you do not want to receive any further information from the group.***

***If you are able to receive the newsletter by email please let us know by sending your details to [president@liversupportgroup.org](mailto:president@liversupportgroup.org)***

### **Keeping Your Vaccinations Up To Date**

**- Simone Strasser, Margaret Gleeson**

A number of routine vaccinations are recommended in people who have had a liver transplant. Some of these vaccinations are recommended only for certain people, although they are safe for all transplant recipients. You should ask your local doctor to arrange for you to have appropriate vaccinations, and let your clinic nurse know that you have had them.

**(See Table Next Page)**

#### **Live vaccinations should not be used after transplantation.**

These include:

- \*Varicella (chickenpox)
- \* BCG (tuberculosis)
- \*MMR (measles, mumps, rubella)
- \*Yellow fever
- \*Oral polio vaccine
- \*Small pox

If you are planning to travel overseas, you should find out whether any vaccinations or health checks are required for the countries you are planning to visit at least 6-12 weeks before your planned departure. Specific information can be obtained from your local doctor or travel clinic.

Live vaccinations should not be used. Further information can be obtained from the Department of **Foreign Affairs and Trade** [www.smartraveller.gov.au/tips/travelwell.html](http://www.smartraveller.gov.au/tips/travelwell.html)

## Appropriate Vaccinations for You

<b>Vaccination</b>	<b>Brands Recommended</b>	<b>Who Should Have It?</b>	<b>How Often?</b>
<b>Influenza</b>	Multiple available	Everyone	Every year at beginning of Winter
<b>Pneumococcal</b>	Pneumovax 23	Anyone without a spleen  Anyone over 65	Every five years
<b>Meningococcal</b>	Menomune Mencevax	Anyone without a spleen	Once only
<b>Haemophilus B</b>	Multiple available	Anyone without a spleen	Once only
<b>Hepatitis B</b>	Engerix-B H-B-Vax II	Anyone without immunity to hepatitis B	Course of 3 injections over 6 months
<b>Hepatitis A</b>	Havrix Avaxim VAQTA	Anyone without immunity to hepatitis A (particularly travellers)	Course of 3 injections over 12-18 months
<b>Combined Hepatitis B plus Hepatitis A</b>	Twinrix	People needing both vaccinations	Course of 3 injections over 6 months
<b>Tetanus/diphtheria</b>	ADT	Everyone	Every 10-20 years



# Membership Application.

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

**City/Town:** \_\_\_\_\_

**State:** \_\_\_\_\_ **P/code:** \_\_\_\_\_

**Phone:** (Hm :) \_\_\_\_\_

(Wk) \_\_\_\_\_

**Email:** \_\_\_\_\_

**Transplant Date:** \_\_\_\_\_

## **NEWSLETTER**

To enable us to produce a newsletter that is of both use and interest, please take a few moments to jot down some notes or questions that you may have;-

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Membership fee is \$5.00 per year per family.

[www.liversupportgroup.org](http://www.liversupportgroup.org) – Email: [President@liversupportgroup.org](mailto:President@liversupportgroup.org) Ph: 0418 231 824  
Postal - 4 Hickory St Woonona NSW 2517 – Ph: 0418231824