THE NEWSLETTER

OESOPHAGEAL PATIENTS ASSOCIATION

Gullet & Stomach Cancer Support

Issue 19

Autumn 2012

Registered Charity No. 1062461

Thank you Jack

Patient Keith Griffin's son, Jack, organised a charity evening in May 2102 which raised over £600. He organised the show from start to finish, hiring the village hall in Gotham, Nottinghamshire and contacting local businesses for raffle prizes and getting tickets printed.

All Keith's family are entertainers. Jack is only 15 and is planning future events for raising funds for the OPA.

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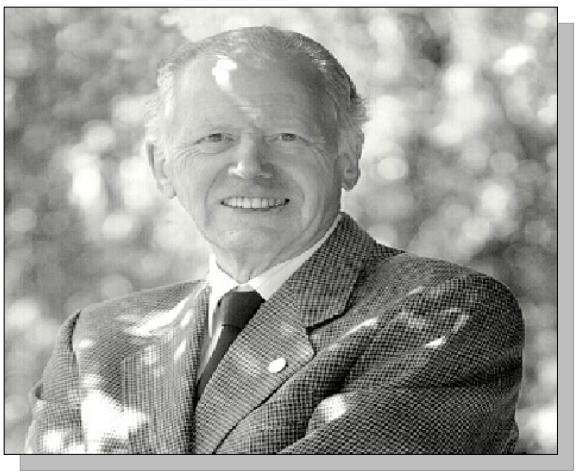
DAVID KIRBY



We were delighted to hear that the upper GI patient support group at Wythenshawe Hospital is celebrating 10 years of activity. They are arranging an event to mark the occasion and I am pleased to have been asked to open the day.

Such patient support groups at hospitals where upper GI cancers are regularly treated are to be welcomed and we will gladly provide our information booklets to the CNS involved. Former patients and carers who are members of such groups and are willing to be more closely associated with new patients/carers must become reasonably knowledgeable and we will help in training of such members if required. We strongly advocate the meeting of new patients with someone who has been through the treatment a few years before as it is recognised that attitude can be influenced to be positive and this can significantly influence recovery.

Quite a number of our branches have been going for many years and it is great to know that patients have such support when they need it. Those involved are all volunteers, giving of their time and support in various ways. In this Olympic year we have become more aware of their importance and I would like to pay tribute to them for their commitment to a very worthy cause.

Within the OPA we are now developing our management structure in order to expand our role and improve our effectiveness in achieving our aims. These are to provide quality information and guidance to new patients and carers; to enable them to meet knowledgeable former patients; to be associated with the medical experts at the major hospitals treating upper GI cancers; and to influence for earlier diagnosis of cancers thus enhancing the UK survival statistics.

A new management team will develop these aims, which are becoming more important as the incidence of upper GI cancers is increasing in the UK. One influence on this incidence is the general increase in the numbers of overweight people and perhaps we can all have something to say on this aspect.

David Kirby
Chairman

REMEMBERING

Rod White, coordinator of the East Anglian Branch of the OPA, sadly died in July just 18 months after his dear partner Pat. He found life difficult without her and his health deteriorated, but he continued to attend Norwich meetings, the largest in the UK with over 120 members present at each one.

He had already handed over the running of the branch to Mike and Loraine Ruddle, who are carrying on the good work started by Rod and Pat 15 years ago, after being inspired by a visit to a Birmingham meeting. A feature of the twice-yearly meetings was a raffle, with the main prize being a shaker-style table made by master craftsman Rod; Daphne and I were never lucky enough to win one but were surprised and delighted to be presented with one a few years ago.

Rod will be much missed, but the Branch, which is so well supported by the medical staff at the Norfolk and Norwich Hospital, is continuing in safe hands.

David.

O. P. A.

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Chris and Sheila Spiller

BRANCH NEWS

I was diagnosed with oesophageal cancer in the year 2000 and had two cycles of Chemo followed by an Oesophagectomy. My wife, Sheila, and I attended OPA meetings in Nottingham until 2004, when we started the Derby-Burton branch. I have been the secretary since then and also co-ordinator from 2005.

Sheila and I originally met at a Scottish Country Dance in Perth. We have continued to dance ever since, and I have been a qualified dance teacher since 1989. I did not let the Oesophageal Cancer stop my dancing or teaching. It therefore seemed appropriate that we should celebrate our Ruby Wedding anniversary with a dance.

We held this dance in Derby, with George Meikle and the Lothian Band (one of the top bands in the UK). We invited all our dancing friends and acquaintances from around the midlands. Over 100 people attended the dance coming from as far afield as Birmingham, Leicester, Leeds and Rochdale. We had a wonderful night of dancing, with many commenting that it was the best dance they had been to for many years. We had some requesting that we organise another similar dance for our Golden wedding if not before!

We asked for donations to the OPA in lieu of cards or presents and received over £766 on the night. With later additions the final donation to the OPA amounted to £910.

Chris Spiller
Derby & Burton Branch

The mailing list for this publication has been drawn from all people who have contacted us for information or support during the last few years.

Please forgive us if its arrival finds you at a difficult time or is distressing in any way.

It is often difficult to know what the current situation is for our contacts if we have not heard from them for a while, but if you want us to remove your details from the mailing list for whatever reason please let OPA know by 'phone, letter or email.

If you are happy to continue to receive contact from us, you need take no further action.

With kind regards, Dawn.

No Christmas Cards for 2012

Unfortunately we will not be selling Christmas cards this year due to the hefty postal price increase by Royal Mail. We apologise for any disappointment this may bring to many of our contacts and thank you for your support in previous years.

Dawn Williams—Patient Support

PATIENT EXPERIENCE

Can we eat now please?

by Larry Rees

It was a blazing hot summer afternoon as I sat perusing the gastronomic delights on the menu at the Waterside Inn - Michel Roux's restaurant in Bray- on Sunday 18th June 2006. It probably took me close to half an hour to make my choices for the sumptuous banquet that was about to commence.

Yet this wasn't my birthday, my wedding anniversary or any other special occasion that merited such a celebration. It was the day before I went into hospital to have an oesophagectomy. Even though I still had cancer, the chemotherapy had successfully reduced the tumour size to such an extent that I ate without any of the discomfort I'd endured in the lead up to diagnosis. It was a wonderful afternoon, shared with my wife, even though we both knew it would be the last time I'd ever enjoy such a banquet again. Well, I *thought* I knew, but there is a huge difference between the notion and the reality.

I often recall that wonderful meal with fondness and I have to admit a degree of sadness and, at times, anger. Eating and drinking is at the very core of social interaction. We fall in love over meals, meet our friends, celebrate at the drop of hat, do business and mark official occasions with banquets. In fact, you'll have around 100,000 meals in your lifetime and, believe me, you take the process for granted. But we don't.

By 'we' I mean those of us who have undergone oesophago-gastric surgery. After a number of complications and 3 months on a feeding machine I was ready for my first meal; from memory, some scrambled eggs. I savoured every mouthful and chewed it up thoroughly as I'd been instructed. Yet to my dismay 30 minutes later I was in extreme abdominal discomfort, doubled up with pain. Those feelings continued for a while and then I urgently needed to go to the bathroom. I didn't know it at the time, but I was undergoing my first experience of dumping syndrome, a condition that I've subsequently come to understand better than most.

Dumping syndrome is actually a really badly named condition. Tell your friends or family that you suffer from dumping syndrome and they imagine that it means that you suffer with a bit of diarrhoea. They fail to grasp the acute abdominal pain, bloating, gurgling, fatigue, sweating and fainting fits that accompany it. It's not called a syndrome for nothing! In addition to the unpleasant physical aspects of dumping the psychological effects are quite devastating.

Now I'm like a man who's scared of his own shadow. Before I do anything I have to consider whether or not I've eaten and what I'm going to do to cope while I'm out. Restaurants are a nightmare as waiting staff interrogate you, thinking you haven't eaten enough. Visits to friends or relatives are met with trepidation in case you have to cope with an attack. Most recently I had a bad attack whilst on an intercity train. I nearly passed out and then spent 40 minutes in the WC, regularly interrupted by the guard checking if everything was ok. I started to realise that there was some kind of connection between sugar/carb intake and dumping syndrome.

So I bought a blood glucose meter and did some experiments. What was most interesting was that I was going hyperactive during and immediately following attacks. At least I knew what was going on, even if I couldn't really do anything about it.

Some months later a talented gastroenterologist (who had extensive experience of dumping from the days of gastric surgery for ulcers) introduced me to liquid loperamide. Astoundingly a couple of squirts before a meal can sometimes prevent an attack. In the same way, I discovered by accident that my increasing bouts of fatigue and lethargy were being caused by low ferric levels once an understanding GP got curious enough to send me for blood tests.

'Googling' the subject led to my discovery that cold press juice extraction is a great way for oesophago-gastric patients to overcome the malabsorption problems that so many of us suffer.

So one by one I was conquering my demons, but I kept wondering what was coming next. I didn't have to wait too long. My periodic tests with the blood glucose meter were indicating that I was becoming insulin resistant.

As I researched around this I started to discover that sugar spikes were the worst possible thing to do to someone who has this type of surgery. I knew about the over production of insulin during dumping attacks and the subsequent hypos that left me reaching for the glucotabs but now I seemed to be developing diabetes.

Another round of frantic 'googling' put me on the path to the glycaemic index and the glycaemic load diet. Suddenly it was all starting to make some sense! If I could control the release rate of sugar and carbs, I might reduce the hit and miss nature of dumping syndrome. I might also avoid becoming diabetic and adding further drugs into my life. I just hate having to remember to take all the pills and supplements!

So why am I telling you all this? It took me several years of dedicated research, trial and error to achieve some level of understanding about the 'new me'. Subsequently I have discussed all that I have learned with a number of specialist dieticians and come to realise that I could have saved myself considerable misery if I'd had one of them by my side.

I have been able to contrast and compare my first hand experiences and experiments with their academic knowledge and found a remarkable confluence between us.

Today I run a support group for those who are undergoing this type of surgery and I do everything I can to get them to consult a specialist dietician. This is a very difficult subject and it is not for generalists. We NEED specialist dieticians who can support and guide oesophago-gastric patients through the minefield. If you don't have them on your team—recruit them. If you do—don't let them go!

Larry Rees is a committee member of the

Oesophageal Patients Association.

Dumping Syndrome

What is Dumping?

The name 'dumping' has been given to a collection of symptoms that occur after a meal in patients who have undergone certain operations upon the stomach. The symptoms fall into two groups. One consists of symptoms that appear to be definitely related to the digestive tract; the patient feels sick, their abdomen feels bloated, they experience borborygmi (tummy-rumblings) and this combination of symptoms sometimes leads to passing a bulky, loose bowel motion. The other group of symptoms is quite different. Patients feel tired and want to lie down, and this may progress until they actually feel faint and sweaty, and are aware that their heart is thumping (palpitations).

What is the Cause?

The cause of these symptoms is that the stomach is emptying its mixture of food and gastric juice into the intestines at a rate that is greater than normal. Normally, when food enters the stomach it mixes with the gastric juice and digestion commences.

The valve at the lower end of the stomach, the pylorus, acts as a brake on stomach emptying, so that the mixture is allowed through only bit by bit. If the valve is removed by surgery, or its function reduced by paralysing the muscle that forms the valve, the mixture gushes through into the intestine and causes the symptoms.

How are the Symptoms Produced?

The same mechanism is involved in the production of both sets of symptoms: it is called 'osmotic pressure'. The partly-digested food mixture contains a larger number of molecules than the food that was eaten because much of the starch in the diet has been broken down to sugars.

A strong solution of sugar in the intestine makes the bowel contract vigorously (producing the tummyrumbling) so that it is rapidly spread throughout the length (20 feet or so!) of the small bowel. A strong solution of sugar then acts like blotting paper to suck water out of the much less concentrated tissue fluids of the body.

It is this sucking effect, which one can think of as an attempt by nature to equalise the concentrations of sugar in the gut and the blood, that is called osmotic pressure. This rapid shift of fluid from the body into the gut has been measured, and can be as large as 1.5 litres (three pints). Part of it comes from the blood itself (the rest from other parts of the body), and the fall in blood volume leads to faintness, sweating, desire to lie down and palpitations. The extra three pints of water in the guts leads to the feeling of bloating, makes the tummy rumbling worse, and if bad enough can end up with the passage of the excess liquid as the watery diarrhoea.

What operations produce dumping?

Surgical removal of most or all of the of the stomach (gastrectomy) nearly always involves the removal of the valve at the bottom of the stomach (the pylorus). This may be for technical reasons or because the disease requires this step. In another operation called a gastroenterostomy the surgeon needs to by-pass the valve by making a communication between the stomach and the part of the intestine beyond the valve.

This may be necessary because the valve is blocked. A third group of patients may have had an operation to cut the vagus nerves to their stomach (vagotomy). This reduces the amount of acid that the stomach makes. Unfortunately cutting these nerves not only reduces acid but also diminishes the muscle power of the stomach and so its ability to empty itself. An operation to increase its drainage overcomes this problem but may lead to dumping. Fortunately modern vagotomy operations can leave the nerves to the valve (pylorus) intact.

How common is dumping?

This is a difficult question to answer because dumping is probably only an exaggeration of what happens in normal life. We are all familiar with the feeling of abdominal fullness and sleepiness which can follow a large meal but symptoms are usually mild. Dumping will be most noticeable soon after the operation and will be made worse by larger meals.

Probably 20-50% of patients who have recently undergone a stomach operation as described above will notice such symptoms, and those who do not probably have the same changes going on inside them, but their circulations are less sensitive to the fall in blood volume and their intestines are less sensitive to bloating.

As time passes the symptoms become less, until by twelve months after the operation fewer than 5% of patients still complain of symptoms. The other 95% may also have them to a minor degree, but have learned to live with them. This means that they have discovered ways of reducing the impact of the condition on their lives.

What is the Treatment?

Firstly, it is worth remembering that dumping usually improves without any treatment at all. If you are still experiencing symptoms a year after the operation, it would be well worth asking for help from your general practitioner or hospital consutlant. Meanwhile, however, there are plenty of common-sense measures that you can take for yourself. Since the symptoms are directly related to each meal, limit the size of your meals: get up from a meal while you can still eat more. To ensure adequate nutrition, increase the number of meals you take. This step is not always easy, especially if it does not fit in with your work-pattern.

Take plenty of vitamins, calcium and iron, because gastric operations may result in a tendency to be short of these. Avoid the feeling of faintness by resting, at least sitting if not lying down, after the meal. The symptoms usually last only 20-40 minutes, so try not to go straight back to your job or housework immediately after the break. Again, this may be difficult to achieve. Think about what you eat. Carbohydrates are rapidly broken down into small particles with a large osmotic effect, so you should minimise your intake of carbohydrates, especially of sugars.

It is best not to have your cup of tea or coffee at the end of a meal, but to defer it for an hour to lessen the amount of fluid entering the bowel.

For Severe Symptoms

If you are one of the few people with severe symptoms that are not adequately controlled by simple measures and which have persisted for more than a year, you should ask to see the surgeon who performed your operation. He or she will probably do a simple test to confirm the diagnosis of dumping, such as testing whether a concentrated glucose solution reproduces the symptoms. It may then be possible to advise if an operation is available to cure your rapid stomach emptying.

For example, if your pylorus has been by-passed it may be possible to bring it back into circuit; if it has been enlarged, it may be possible to restore it to normal size; and if your stomach has been removed, it may be possible to construct an artificial stomach from intestine. If no operation is available, drug treatment may be recommended. There is no one remedy that is so good that it has displaced all the others, but each has helped many patients so it is well worth trying what you have been prescribed.

Useful Tips on Diet

1. Eat small frequent, regular meals 2. Only drink between meals.
3. Avoid too much sugar and sugary foods. If necessary, you can use artificial sweeteners.
4. Avoid excesses of acidic foods eg. Tomatoes and citrus fruits.
5. Excess fat should be avoided
6. Try not to eat late at night.
7. Avoid food temperature extremes.
8. If you are underweight seek advice from a dietitian regarding energy and protein supplements.
9. Increase foods rich in calcium and Vitamin D.
10. Iron, folic acid and Vitamin B12 supplementation may be necessary.

· Reproduced from Core Digestive Factsheet No.6

The Glycaemic Index

What is it?

The Glycaemic Index (GI) is a ranking of foods based on their overall effect on blood glucose levels. Slowly absorbed foods have a low GI rating, whilst foods that are more quickly absorbed will have a higher rating. This is important because choosing slowly absorbed carbohydrates can help even out blood glucose levels when you have diabetes.

Foods are given a GI number according to their effect on blood glucose levels. Glucose or white bread is used as the standard reference (GI=100), and other foods are measured against this. The effect on blood glucose levels of a portion of the test food containing 50g of carbohydrate is compared with the effect of the reference food (white bread or glucose) over a three hour period. It was previously thought that if you ate the same amount of carbohydrate, then whatever that carbohydrate was, it would have the same effect on your blood glucose levels. It is now known that different carbohydrate-containing foods have different effects on blood glucose levels. For instance, 30g of bread does not have the same effect as 30g of fruit or pasta.

What are the benefits of slow acting carbohydrates?

Because meals including low GI foods allow you to absorb carbohydrate more slowly, they help to maintain even blood glucose levels between meals and can therefore help you avoid 'hypos'. The effect of a low GI meal can run into the following meal, which helps keep blood glucose more even during the whole day.

Slow acting carbohydrates will also reduce the peaks in blood glucose that often follow a meal, and this may have a role in helping to prevent or reduce the risk of getting Type 2 diabetes in those at risk. There are also benefits for weight loss. Low GI foods can help you to control your appetite by making you feel fuller for longer, with the result that you eat less. Research has shown that people who have an overall low GI diet have a lower incidence of heart disease.

Lower GI diets have also been associated with improved levels of 'good' cholesterol. One or two small changes can make all the difference.

Does anything else affect GI?

Yes. Determining the GI of a meal is not so easy as reading a number off a chart. The addition of fat and protein slows down the absorption of carbohydrate. Chocolate has a medium GI because of its fat content, and crisps and chips will actually have a lower GI than potatoes cooked without fat. Milk and other dairy products have a low GI because of their high protein content, and the fact that they contain fat. The consequence of this is that if people were to confine themselves to low GI foods, their diet would be unbalanced and high in fat, which could lead to weight gain and increase their risk of heart disease. For this reason it is important not to focus exclusively on GI and to think about the overall balance of the diet.

Cooking method (frying, boiling and baking), processing, the ripeness of a fruit and the variety of a vegetable will also all affect a food's GI rating. The structure and texture of a carbohydrate have an effect as well. Pasta and durum wheat have a low GI rating, whilst whole grains and high-fibre foods act as a physical barrier that slows down the absorption of carbohydrate. This is not the same as 'wholemeal', where, even though the whole of the grain is included, it has been ground up instead of left whole. For example, some mixed grain breads that include wholegrains have a lower GI than either wholemeal or white bread.

Can I get hold of a list of GI values for all foods?

There are books that give a long list of GI values for many different foods. This kind of list does have its limitations however.

The GI of a food only tells you how quickly or slowly it raises the blood glucose level when the food is eaten on its own. In practice, we usually eat foods in combination as meals – bread is usually eaten with butter or margarine, or as an accompaniment to a meal, for example; potatoes are often eaten with meat and vegetables.

So cutting out all high GI foods is not the answer. The good thing is that you can apply the GI concept to lower the overall GI of a meal by including in it more low GI foods. You need to think about the overall balance of your meals, which should include starchy foods and be low in fat, salt and sugar.

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OESOPHAGEAL PATIENTS ASSOCIATION

Food Diary

Mon Tues Wed Thurs Fri Sat Sun

To help you understand the triggers that may bring on your own particular symptoms of Dumping Syndrome we have produced a Food Diary which is available on request via email, telephone or letter. The Food diary is also available to download from our Website www.opa.org.uk

Meetings and Dates for your Diary

With the ever increasing list of support groups available to you around the country the dates and times together with contact details will now only be available via our website.

Please accept our apologies if you do not have access to the internet, please contact us on 0121 704 9860 and of course we will help in any way we can.

Newsletter by E-mail

Due to an IT glitch we were unable to send out this newsletter to those that requested it as an electronic version. This problem will be sorted by the time the next newsletter is due. Thank you for your understanding.

IF YOU HAVE A STENT FITTED

Modern stents are made of mesh wire, generally covered with a thin material. They are easy to insert being encased in a pencil-thin sheath before release opposite the constriction. They usually cannot be taken out again. They come in different internal diameters (usually 9-12 mm) and lengths to suit individual needs. Generally they are held in place by the constriction they are opening up.

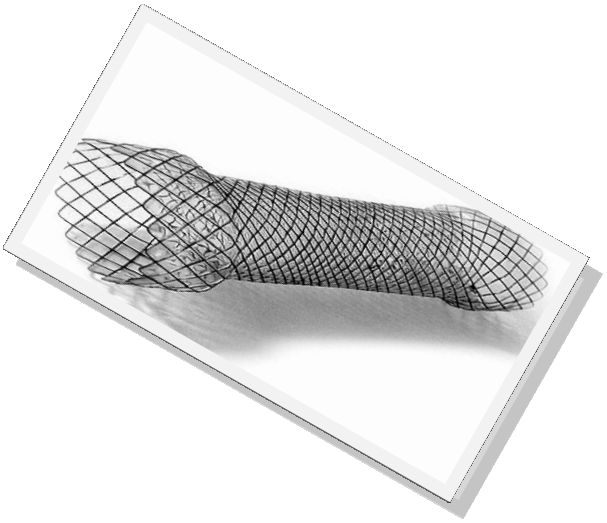
Looking after the stent:

- Don't rush eating
- Have soft food in small mouthfuls and chew it well
- Drink a little during and after meals—fizzy drinks are helpful
- Sit up straight when eating
- Don't tackle large lumps of food—cut them up small and chew well
- Spit out anything not chewed
- Mix food such as Complan very thoroughly—dry powder will block the stent.
- If you feel the stent is blocked stop eating, drink a little and walk around
- If the blockage persists for more than 3 hours ring your GP or contact the Hospital you were treated at.
- Clean the stent after eating with a fizzy drink
- Keep teeth and dentures in good order so that chewing is effective

FOODS TO AVOID

- Green salads and raw vegetables
- Fried egg white and hard boiled egg
- Fruit skins and pith of grapefruit and orange
- Tough meat and gristle
- Fish with bones
- White bread, crusty bread and toast
- Shredded Wheat and Puffed Wheat
- Hard chips and crisps
- Nuts and dried fruits

A Basic Oesophageal Stent



USEFUL INFORMATION AVAILABLE FROM YOUR OPA

There are three booklets created and published by the Association for the benefit of members:

The Oesophageal Patients Association (who we are and what we do).

Swallowing – Nutrition When It's Difficult

A Guide to Life after Oesophageal/Gastric Surgery.

We also have factsheets on advice for relaxation and sleeping available from the Association.

The Association can also provide Restaurant and Toilet cards which are available to use in most European countries.

Please call the helpline on 0121 704 9860 or email **enquiries@opa.org.uk**

Other Information is also available from:-

www.macmillan.org.uk & www.corecharity.org.uk

ROTARY CLUB DONATION

The Wadhurst Rotary Club in East Sussex has made a donation for the awareness campaign.
For further details please visit:-
www.actionagainstheartburn.org.uk

Andrew Collins {left} of Wadhurst Rotary Club presents a donation of £1,500 to Alan Moss, Co-ordinator of the London Branch, to kick-start the campaign.

✂----------

Donation Form

I am pleased to send a donation of **£** Date of donation **/ /2012**
(Please make cheques payable to OPA and complete your details below)

If you are an income tax payer, tick here _____ which will enable OPA to recover tax on this and any future donations you may make, under the *Gift Aid Scheme*, provided you have paid income tax or capital gains tax equal to the tax reclaimed by the OPA on the donation(s) in the tax year.

FROM:

Mr/Mrs/Miss/Other: .....

NAME:.....

ADDRESS:.....

POST CODE: .....

TELEPHONE NUMBER:..... **EMAIL ADDRESS: .....**