CAUTION – The 'Author' of this note has no medical experience, you must either make your own decisions or seek medical advice from a qualified medical practitioner before following any of the information in this note.

The following information has been produced in the hope that it may be of some benefit to other people suffering from cancer.
Whilst some information was provided from the medical staff we felt that it was woefully inadequate and poorly delivered. If you want my view I think that each patient should be given an information pack, ideally specifically tailored for them, if not then generic for their condition. Jean did not receive a diet sheet until 2 weeks after radiotherapy had been delivered, I could go on.
Some people will advise against believing what you read on the internet, personally we found it an invaluable source of information, and to be honest I think a 'drowning man will clutch at anything'.
Remember that each cancer is unique; because some of the following worked for Jean it does not mean that it will work for you.

Background

At the time of treatment Jean was a relatively fit but not sporty 49 year old, size 12, nine and half stone, Caucasian, fair but lightly tanned skin.

Jean visited the oncologist in January 2008. To cut a long story short the news was pretty much as we had expected – not good but he is hopeful.

The PET scan had confirmed the previous diagnosis i.e. the rectal Tumour which was described as aggressive, lesions in the liver which were described as very small and the peri-aortic lymph nodes which are serious - more later. For location of these nodes see http://en.wikipedia.org/wiki/Paraaortic_lymph_node
For the technical the Cancer is described as Grade 4, the highest, and on the TNM scale T3, N3, M1. For more info see this http://en.wikipedia.org/wiki/TNM

Consequently he advised that the diagnosis was not quite as hopeful as originally thought however he does have a plan. Dr Geh specialises in a combination treatment of Chemo and Radiation therapy. The plan is therefore an intensive 5 week treatment of Radiation, plus intensive Chemo in the first and last weeks, at which time Jean will receive 2 types of Chemo. Because of the way the Chemo is delivered this will mean that Jean will have to stay in hospital, the Queen Elizabeth in a Private Ward. Clearly Chemo can have many side affects some of which may manifest themselves, I won't go into them here.
The Radiation is likely to lead to some soreness in week 3 this would be like sunburn with peeling and scabbing. Recovery should take 7-10 days.

This treatment will largely only deal with the tumour, hopefully the Chemo will attack the lesions in the liver and may attack the peri-aortic lymph nodes. Another PET scan will be needed after the 5 week treatment to ascertain how these other 'organs' have reacted at which time additional treatment may be required. He may possibly try radiation on the lymph nodes.

We found this information on the Macmillan cancer site very useful – caution some of the information on the site can be quite frightening.

Extract from the Macmillan site – courtesy of lovetogardenfi whose advice was very useful to us.
http://share.macmillan.org.uk/Share/Forums/Default.aspx?topic=1003036&goto&page=0

Radiotherapy - when you are having the treatment you need to have cleaned the area with plain water at least an hour beforehand. Any creams or residues of soap can cause burning. After the radiation, apply large amounts of aqueous cream to the whole area. When, after about two weeks, the skin begins to become sore you can switch to Emulsifying Ointment (available in tub from Boots) which is very pure, thicker than aqueous and does not sting - you can wash with it under the bath water. Side effects - gradual redness of area, loss of pubic hair, eventual lifting of upper layers of skin, possible blister/ulcers, peeling leaving raw and sore areas: coat these with emulsifying ointment in the bath and pat dry very gently. The skin will continue to peel until about two weeks after treatment, keep up the moisturising with the emulsifier, or aqueous where skin has healed.

The first week of radiotherapy is likely to be the most dramatic - I found. By the 4th day I had diarrhoea, mixed with blood clots - I was told this was very likely the actual tumour breaking down. Hoorah for that - but quite alarming and I began to feel quite weak - at the same time as the effects of the chemo put me off eating too. Radiotherapy makes you very tired - after each dose I managed a drink and a slice of toast (lived on toast and cornflakes, and Ensure drinks throughout) then a few hours sleep every day, as an outpatient too. You might want to stock up on Tesco Freestyle pads which protected me in the car from 'accidents' - also sitting on a towel was reassuring and softer. Chemo after a few days makes you tired, and feel sick - it puts you off your food. I drank plenty of water, but still was dehydrated at the end of the week - if he feels weak and faint, ask them to check if he needs saline. The GP is the one for the rest of your needs as you will find the hospital treats you for chemo and radio, but it's very much up to you to find help for the side-effects and general well being. My GP gave me a prescription for paracetamol, ibuprofen, Ensure build ups. The main point is - with the number of staff available they are stretched, it is up to you to voice Chris's needs to get help, I learnt this the hard way - my second stay in hospital was much better than the first. The first I was in a side room, largely ignored which was not good - he will be better in the main ward where the nurses can see him.

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http://share.macmillan.org.uk/Share/Forums/Default.aspx?topic=1001459&goto&page=6

My heart goes out to you for these last few days - unlike giving birth, I do remember the soreness and discomfort. I used emulsifying ointment (comes in a tub from Boots) which you can use under the water so that it's really soft and stays on if you just barely pat yourself dry. I used this the whole time until the skin repaired itself - in record time the consultant said, so must have been the right thing. A shallow, salty lukewarm bath every morning and evening too (driest skin ever on my legs, but nothing compared to the relief). They told us not to wear panties - but I found there was too much 'going on' (sure you know what I mean) so I either cut the elastic out of the crutch area of my pants, or wore those short style ones which aren't elasticated on the inside. For accident avoidance - Tesco Freestyle pads (they're cupped so hold everything in!), next to the Tena expensive stuff. The diarrhoea went off after about a week after radio finished - avoid fatty or spicy food, eat everything white and plain. Drink gallons of water and if Imodium doesn't work, try Codeine (helps with pain as well). I took alternate paracetamol and Ibuprofen every two to four hours so they lasted me the whole 24 hours. There a few more tips for the as yet uninitiated!

Diet

Initially Diarrhoea was a big problem for Jean. We eventually managed to obtain a diet sheet which is reproduced here. A second diet follows, Jean actually found the second diet better and once she stopped milk, she only had milk on cereal in any event, things quietened down quite a lot. She also used Imodium, or a variety of (Loperamide), which your doctor can prescribe.
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Produced from a diet sheet provided by

The Cancer Centre
Queen Elizabeth Hospital

LOW RESIDUE DIET

RADIOTHERAPY DEPARTMENT

While you are having radiotherapy, it is important that you temporarily reduce your dietary intake of residue (fibre) to avoid irritation of your bowel. As this diet is low in vitamin c, it is important that you have a glass of fruit juice/Ribena, to compensate.

DO'S

The following groups of food contain little fibre and can be taken freely:

MEAT	All types – cooked in any way
FISH	All types – cooked in any way
EGGS	Cooked in any way
CHEESE	Cheddars, plain cottage and cream cheeses
CEREAL/BREAD	Cornflakes, rice krispies, strained porridge, white bread, cream crackers, biscuits made from white flour, plain cakes, rice macaroni, spaghetti, noodles
BEVERAGES	All types – as desired
FRUIT	Pure fruit juices only
VEGETABLES	Potatoes creamed or boiled only. Tomatoes – remove skin and pips
FATS	As desired
SEASONINGS	Salt, pepper, sugar, milk shake syrup
PRESERVES	Jelly jam, clear honey, syrup
DESSERTS	Custard, rice, tapioca, ice-creams, jelly, blancmange, instant whip puddings
MISCELLANEOUS	Boiled sweets and chocolates

DON'T'S

The following foods contain residue/fibre and should be avoided in order to minimise the possibility of diarrhoea:

CHEESE	Containing nuts, seeds, vegetables
CEREALS & BREAD	Whole grain cereals, brown breads and any products made from wholemeal flour – such as digestive biscuits
FRUIT & VEGETABLES	All types – tinned – frozen or fresh
SEASONINGS	Avoid very spicy dishes, such as curries or pickles
PRESERVES	Fruit jam and chunky marmalades
DESSERTS	Any made from wholemeal flour or containing fruit, skins or pips

SAMPLE MENU

BREAKFAST	Pure Orange juice Strained porridge or cornflakes, rice krispies Egg, bacon, fish, skinned or pipped tomatoes White toast with butter and/or marmalade
MID MORNING	Tea or coffee, plain biscuit
LUNCH	Pure fruit juice/strained soup Meat or fish, eggs or cheese Mashed or boiled potatoes or bread Jelly and ice-cream or milk pudding
MID AFTERNOON	As mid morning
EVENING MEAL	As lunch
BEDTIME	Tea or coffee with biscuit if desired

If you would like any further advice on your diet adjustments during treatment, please let either your radiographers or the radiotherapy nurses know and they can make arrangements for you to see the hospital dietician.

03/02/2008

There is a possibility that radiation can cause enteritis, it is not a foregone conclusion, and I mistakenly thought that this was what was happening to Jean.

The role of nutrition in acute enteritis

Damage to the intestinal villi from radiation therapy results in a reduction or loss of enzymes, one of the most important of these being lactase. Lactase is essential in the digestion of milk and milk products. Although there is no evidence that a lactose restricted diet will prevent radiation enteritis, a diet that is lactose free, low fat, and low residue can be an effective modality in symptom management.[3]

Recommended foods to avoid:

- Milk and milk products. Exceptions are: buttermilk and yogurt, which are often tolerated since lactose is altered due to the presence of lactobacillus. Processed cheese may also be tolerated since the lactose is removed with the whey when it is separated from the cheese curd. Milkshake supplements, such as Ensure, are lactose free and may be used.
- Whole bran bread and cereal.
- Nuts, seeds, coconuts.
- Fried, greasy, or fatty foods.
- Fresh and dried fruit and some fruit juices, such as prune juice.
- Raw vegetables.
- Rich pastries.
- Popcorn, potato chips, and pretzels.
- Strong spices and herbs.
- Chocolate, coffee, tea, and soft drinks with caffeine.
- Alcohol and tobacco.

Foods to encourage:

- Fish, poultry, and meat that is cooked, broiled, or roasted.
- Bananas, apple sauce, peeled apples, apple and grape juices.
- White bread and toast.
- Macaroni and noodles.
- Baked, boiled, or mashed potatoes.
- Cooked vegetables that are mild, such as asparagus tips, green and waxed beans, carrots, spinach, and squash.
- Mild processed cheese, eggs, smooth peanut butter, buttermilk, and yogurt.

Helpful hints:

- Ingest food at room temperature.[2]
- Drink 3000 cc of fluid per day. Carbonated beverages should be allowed to lose their carbonation prior to drinking.
- Add nutmeg to food, which will help to decrease mobility of GI tract.
- Start a low residue diet on day 1 of radiation therapy treatment.

Although the diet sheet recommends against spicy foods we found this information which is reinforced on many sites but mainly as an anti cancer food.

http://news.bbc.co.uk/1/hi/health/2308745.stm

A spicy ingredient of many curries may be an effective treatment for radiation burns, according to a study.
Researchers in the United States believe it may prevent skin blistering and redness associated with cancer radiation therapy.
The compound, which gives the spice turmeric its yellow colour, was effective in tests on mice.
Turmeric is found in everything from mild Kormas to the hottest Vindaloos. The crucial chemical - curcumin - has long been used as a traditional medicine.
It is now being investigated for the treatment of colon cancer and Alzheimer's disease as well as burns.
In the latest study, a team at the University of Rochester's Wilmot Cancer Center tested the ingredient on 200 mice. Mice given curcumin had fewer blisters and burns after a single dose of radiation, said Dr Ivan Ding, who helped carry out the study.
"If a non-toxic, natural substance can help prevent this damage and enhance the effectiveness of our radiation, that's a winning situation," said team leader Dr Paul Okunieff, chief of radiation oncology at the university.

'Encouraging'

The authors of the US study warn that curcumin must be tested in other animals, and then in people, before it is accepted as valid.

The spice is thought to work as an anti-inflammatory agent. It is said to have a number of other health benefits, such as aiding digestion and helping fight infection.

Professor Andy Gescher of the department of Oncology at Leicester University, UK, is part of a team testing curcumin capsules on colon cancer sufferers.
He believes there is anecdotal evidence to suggest that members of the Asian community in the city may be better able to resist colon cancer because they use the spice in cooking.

The results of the US study were "very encouraging", he said.
"It's not surprising that agents like curcumin have beneficial effects in a large number of areas of health," he told BBC News Online.

Useful sites

Wikipedia – various re radiotherapy, TNM ratings etc.

www.Cancerbackup.org.uk for lots of info re drugs etc. - excellent

www.macmillan.org.uk again lots of information

www.redcross.org.uk/shop/product.asp?id=59460

http://blogs.ebay.com/drlspears/entry/Dry-Skin-Cancer-Radiation-Burns-Biafine-Cream-Hone/_W0QQidZ241879014

Medication

One of Jean's biggest problems was stress, this would keep her awake at night, and consequently we sought some sleeping pills. I always thought that sleeping pills knocked you out but not in Jean's case.
Initially Jean took Temazepam 10mg. One wasn't enough so she was taking 2 circa 23:30, and then another circa 3:00.
Nitrazepam was recommended by a friend who is a GP but never prescribed.
She was subsequently prescribed Zolpidem 10mg with much the same effect.

Lansoprazole was prescribed for antacid

She took Paracetamol and Paracetamol Plus (with caffeine) for pain relief.
Co Codamol and Codeine were also prescribed for pain relief. This can have constipatory effect.

Imodium (Loperamide) for diarrhoea.

We should have known, but we didn't that you can Pre Pay for Prescriptions in the UK. This works out at the time of writing at about £26.70 for 3 months £96 for the year.
No one told us until week 6. The chemist will provide a pre pay form to enable you to contact them.

Skin

According to some of the sites radiation burn is more like a chemical burn than sunburn, however you will certainly see a reddening in the area where the radiation is targeted, this can be quite painful see earlier notes and there are some horror stories out there.
I repeatedly asked before treatment started if there was anything we could do or apply, e.g. get a suntan, apply cream etc, and was advised not. If you look on the internet I don't believe that this information is strictly true, I would say "there is nothing that we do in the UK", other countries have different approaches. Similarly it would appear that once radiotherapy starts in this country we don't stop, whereas in the USA, in some states, they do, giving a few days break and thus time for the skin to recover.

The only cream that Jean was supplied was hydrocortisone. We had followed the advice given by lovetogardenfi (see above) and purchased both E45 and Emulsifying Ointment BP made by Pinewood from Boots. In both of these cases we did ask the consultant if it was ok to apply the cream. The nurses may give you a different answer and to be honest I am not sure anyone really knows. The only thing I would say for sure is do not apply within 4 hours of treatment. Jean applied E45 cream immediately and I mean immediately after treatment. As a result the skin broke at about treatment 18, so late in week 4. The doctors and the nurses said she had either been very lucky or had been doing something right. Also see the note above about turmeric which Jean took on a daily basis from middle of week 2.

There is also quite a lot of evidence out there in support of a radiation cream called Biafine. If only we could have got some earlier, some studies appear to indicate if used from day 1 it can act like a prophylactic, it's not available in this country but is available in France. A friend of ours got us some start of Jeans week 4 and Jean was happy with the results. It appears to be prescribed as a matter of course in Canada. French women use it for burns and also as a beauty product (which is not recommended) it does not protect against the sun but rather 'takes the heat' out of the burn. Due to the generosity of our friend I can't advise on the price but I think it's about 8 Euros approx £6, at the time of writing, for a sizeable tube 186g

Although when Jean's skin broke she was advised to stop applying creams to the broken skin and apply Gentian Violet, which prevents infection, she continued to apply Biafine to the areas where 'sunburn' was visible but not broken skin.

I thought we had been very clever or lucky, but to be honest we were chumps. Jeans treatment comprised her lying face down on the bed, she would be zapped on the backside then the radiation arm would swing under the bed and zap her from underneath. Because of the horror stories we had read and the advice we were being given we neglected the pelvic area at the front and in reality this gave Jean far more problem than the bum area. If you think of the worst sunburn you have ever seen on holiday then this was worse, the 'burn steadily increased to a peak at about day 7 after radiation had stopped, then began to steadily improve. In Jeans case an area of diameter approx 8" or 20cm in the front pelvic region. Depending on the nature of your treatment you may feel some considerable burning or heat. To this end a strategically applied bag of frozen peas/beans etc wrapped in a suitable cloth e.g. a pillowcase, and then applied as necessary could bring welcome relief. I'm sure that you could purchase gel pads etc but many sites, and the advisor from the women's clinic at the QE, appear to recommend this trick. We were given Flamazine for this and Jean used a combination of creams depending on whether the skin was broken or not.

Side Effects

Where do you start, in no particular order: Constipation; diarrhoea; hair loss or thinning; burning; indigestion, stomach cramps; cystitis, tiredness or lethargy. Jean was best in the mornings but she invariably wanted to lie down in the afternoon after radiation and many other people report feeling very tired.
Jean would like to have continued at work but she couldn't. She didn't feel 'safe' away from me, plus with the radiotherapy, the diarrhoea and the tiredness she stayed away from work. She was able to work remotely from home, my utmost respect to anyone who does manage to carry on as normal.

Clothing

If you're having chemo depending on how and where it's being delivered you may find that night dresses with wide sleeves are best, in order that the chemo bag can be passed down the sleeve.
Depending on how long the chemo is being delivered for, given our time again I think we would consider the following, get a cheapish zip up fleece or cardigan (Sainsbury's had some at £6.00) then as soon as you know which arm cut the sleeve and side and fix either Velcro or some other easy fastening. This will enable the patient to wear something warm which can easily be put on and off. I guess a 'poncho' could have the same affect.

You will also see from lovetogardenfi's note that getting air to the exposed area is a good thing. Jean went without underwear for the 5 weeks. We specifically purchased a couple of cheapish cotton skirts to allow the movement of air. Jean's intention was to burn all of these items when she had finished the treatment.

Travelling and sitting

Jean tried to avoid sitting for long periods and tried to lie rather than sit. We did purchase a Dunlopillo ring cushion for travelling in the car to and from hospital. This worked out about £17.50 inc delivery from the Red Cross www.redcross.org.uk/shop/product.asp?id=59460

Partners

I'm not sure what I can say here really, clearly partners are there to help and support in this very difficult time. There will be times when you feel that whatever you say is not right but as a partner your support is invaluable. Jean and I were fortunate that until now, neither of us had had any serious illness during our 20 years together, so it was a new experience for us both. People kept asking me how I was and I would dismiss their questions but it does take its toll, your lifestyle may well be disrupted; going out, meals and meal times. I was fortunate in working for myself from home and so my work was barely affected. I am not sure what we would have done if I was in full time employment. And of course it can be very upsetting, seeing Jean upset would get me upset.

Photographs

This may sound completely bizarre but…
In Jean's case there was lot of pain and consternation during and post treatment. So there were questions like "is this much redder than usual?", "is this swollen?" etc. To be honest I didn't have a clue and neither did Jean as it was not our regular practice prior to this problem to examine her bits back and front. Hence why I say in this day and age with digital photographs and no necessity to get photographs developed, take some, I know it would have been a useful reference point for us, and on reflection I am surprised that the doctors don't take some, if only to allay patients fears that visibly things are returning to normal.

Support

I have to say that this rankles with me, Jean was with BUPA and so our consultations and theoretically the treatment were private, but throughout all of this we were under the impression that the local surgery and the GP were being kept informed. Somehow Jean managed to fall through the cracks, and the private treatment is blamed. A Macmillan nurse is attached to the surgery and should have been assigned to Jean from 'day one'. After a couple of kindly neighbours with nursing experience got involved we contacted Macmillan and a nurse eventually arranged to see Jean in the middle of Jean's 'week 7', early March. She was supportive helpful and advised that she had not seen radiation burns like this in years.

Hope some of this has helped and best of luck with your treatment

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