

# *The Full Spectrum*

*Living with oesophageal cancer*



*Nola Herrmann*

*Accepting my diagnosis of oesophageal cancer in May 2011 didn't mean that I had to resign myself to the disease. In a situation where so many things were out of my control I found some practical things that I could do while my body played host to the chemo drugs and radiotherapy which I hoped (along with my family and friends, doctors and nurses) would see me cancer-free; a healthy survivor. I'm sharing what I discovered in the hope that some of it will be helpful to others of you facing this disease. I realise that your cancer journey will be as unique as you are and that your experiences, preferences, choices, sense of humour and beliefs could be very different from mine. Please know that I am not meaning in any way to minimise what you are going through, but rather see this as a spring board for your own ideas on how to cope best in your situation. I did not have surgery, a nasogastric tube or a PEG (Percutaneous Endoscopic Gastrostomy/ feeding tube) so I can't comment on the logistics or complications of those. A few of my suggestions are gender-specific – men, you'll know which ones to ignore. Some of the information here pertains to Hamilton, New Zealand.*

*As humans we are complex beings and our health and wellbeing is multifaceted, so it makes sense to me to take a multifaceted approach to achieving it. The term 'holistic medicine' is sometimes used alongside terms like 'naturopathy' and 'alternative medicine' but I think it fits better with the term 'complementary medicine' in which there is room (should you choose them) for life-saving drugs, scans and surgery to support, and be supported by, healthy living. I see it as ministering to ourselves as a whole person and, while it is hard to separate such interdependent aspects of ourselves, I have tried to organise the information below under some headings that relate to the different facets of who we are.*

*Although I know that this cancer has a poor prognosis, I have found that there is much to be hopeful about. I am grateful to be currently enjoying wonderful health and I'm learning to live with uncertainty. I hope you'll find joy in the discovery that in a situation where you sometimes feel very helpless, there is a lot you can do.*

*This comes with my love,  
Nola*

*(October 2012)*

# *Your Body – physical wellbeing*

## **Diet suggestions**

Good nutrition is such a key factor in coping well physically (as well as mentally and emotionally) that it's well worth getting started on this as soon as possible. Even when most food often 'gets stuck' you can still enjoy fine fare – it will just take a different form for a while.

- Because you may have had swallowing difficulties for some time before discovering the cause, you could already have lost weight and condition by the time you receive a cancer diagnosis. If so, it's important to request your doctor's referral to the oncology dieticians at the hospital without delay. They can arrange a consultation and may even agree, in the meantime, to post you a prescription for the dietary supplements, Ensure Powder®, Sustagen Powder® and Fortisip Powder®. To determine your preference it's worth trying them all and in the various recommended strengths i.e. 1cal/ml, 1.5 cal/ml and, in the case of Fortisip Powder®, 2cal/ml (which is a bit like having a thick shake). All are available in chocolate and vanilla flavours and are fully funded. Your dietician will obtain the necessary Special Authority numbers for this funding. Also available are the ready-to-drink products Fortisip® (in bottles - 6 flavours) and Ensure Plus® (in tins), both of which are partly funded (so cost you about \$1.50 per unit). Fortijuice® is not funded (as it's not a complete food supplement) but it is available (an ... 'interesting' taste!). Be sure to also ask the dieticians for their booklets on 'Soft diet', 'Blended diet', 'Ideas to increase your calorie intake' and 'Protein Foods' as well as the booklets of recipes incorporating Ensure® and Sustagen®.
- Aim for nutrient-dense as well as calorie-dense foods.
- Avoid commercially processed foods as much as you can.
- Choose fresh (or frozen) whole food - raw or lightly cooked when possible.
- Wash all fresh fruit and vegetables well.
- Include nuts and seeds when you can – choose ground varieties if necessary and add to cereal, yoghurt or custard. A mixture of ground linseed, sunflower and almond (LSA) is available in the Healtheries range.
- Be careful with chia seeds – they have great nutritional properties but swell up enormously and could block your oesophagus. The same applies to bulk-forming laxatives (e.g. Konsyl-D®).
- Remember to include a variety of grains (wheat, rice, oats, corn, quinoa, etc.) and pulses (lentils, peas and beans).
- Even pips in berry yoghurt can clog what might be a tiny 'funnel' at times; strain them out or stick to the smooth varieties when you have to.
- Include plenty of good protein sources every day
  - e.g. eggs - soft-boiled, poached or lightly scrambled
  - in hot milk with cinnamon, vanilla and brown sugar \*
  - fish - especially salmon, tuna, sardine, mackerel, pilchard, cod, anchovy (Peck's Anchovette® fish paste available in South African section of supermarkets)
  - chicken - make soup or chicken liver pate \*
- Consider buying or borrowing a juicer and a stick blender to help you process your food according to what you can swallow. Your ability to eat

*solid foods may decline during treatment, and for several weeks afterwards, before it begins to improve.*

- *Experiment with juicing your favourite mixtures of fruits and vegetables. Make more than you need and, to preserve the nutrients, freeze what you're not going to use immediately in small portions. The little glass bottles with gold screw lids that iced coffee comes in are ideal (but don't overfill). Defrost one as needed.*
- *Purees can be frozen in ice-cube trays and stored in labelled freezer bags. Defrost when needed and create some interesting mixtures.*
- *Learn to eat little and often (it might feel like constantly). Forget about 'meal times' but do eat when the rest of the family are eating. Blend a bit of what they are having when you can – there won't be any competition for your portion.*
- *Prepare food to eat/ drink even when you don't feel hungry and persist in sipping your way through it – even if some days it takes ages and all the determination you can muster.*
- *For a change of texture try making your home-made fruit/ vegetable juices into jellies using gelatine.*
- *Freeze fruit juices (with or without yoghurt added) into ice-blocks or slushies for a pleasant change (when you can tolerate the temperature).*
- *If you need a blended diet when in hospital consider taking food/ drinks with you to add variety to what is available on the menu. There is a communal kitchen on the ward with a fridge/ freezer and microwave. Your family can restock your 'larder' when necessary. Take along your stick blender and a little bowl. If you like your Ensure® very cold then pop in an ice tray too. Label your supplies with your name and remember to take what you don't use home with you. A bag with a handle works well for carrying all your items (as it can hook over your drip stand leaving you a free hand to steer back to your room with your concoction).*
- *Take your powdered food supplement with you to hospital if the one you like isn't the one currently on the hospital formulary.*
- *Many foods may be too acid to tolerate when having treatment so leave them out. If it hurts to eat/ drink almost everything, a sip of 'Pink Lady' may help as it numbs your mouth and oesophagus. This is a mixture of Mylanta Suspension® (antacid) with a little Xylocaine Viscous® (lignocaine). Be careful though, when using it, that things don't 'go down the wrong way'. The ingredients for this mixture are almost fully funded on prescription. It works well to make up about 20ml at a time in a medicine measuring cup. Discard any unused portion after 24 hours. Sometimes it's quite handy to have some beside your bed at night too.*
- *Following chemo, if your white blood cell count is low (neutrophils specifically), you will be vulnerable to infections that would not be a problem when you are healthy. It's wise at these times to be careful about what you eat. NZ Food Safety Authority produces a useful booklet called 'Food Safety when you have Low Immunity'. (See the list of websites below or phone 0800 693721).*
- *If your mouth is sore, drinking through a straw might help.*
- *Food sometimes tastes different when you are receiving chemo. Eating with a plastic spoon or fork instead of a metal one seems to lessen this effect a bit.*
- *Get reasonably accurate bathroom scales and record your weight each day at about the same time.*
- *Keep a food diary – it helps to identify any gaps in what you are eating.*

- *Despite the fact that, at various stages of your treatment, some foods will clog and others will burn, try to include as wide a variety of food as possible.*
- *Be aware that eating beetroot can colour your urine and stools red. Taking a vitamin supplement that contains vitamin B2 (riboflavin) may give your urine a neon hue. These effects are not cause for alarm.*
- *Aim to 'eat a rainbow' every day. Here are some suggestions to spark your own ideas:*



- *tomato soup (home-made ideally, but tinned is better than packet mix) – add cream/ coconut cream to take the edge off the acidity*
- *strawberry/ raspberry/ stewed rhubarb puree with ice-cream/ yoghurt/ panna cotta*
- *watermelon slushy (blend with the pips if you can – they have some nutritional value but might clog)*



- *carrot, pumpkin and kumara soup*
- *baked beans blended with their tomato sauce*
- *mango pulp (big tins available in Asian shops) mixed with natural yoghurt*
- *carrot and apple juice (with fresh ginger)*
- *pawpaw (papaya) puree*
- *rock melon puree*





- *tinned creamed corn, blended*
- *stewed apple or pear puree, blended*
- *dhal (red/ yellow lentils slow cooked with mild spices including tumeric) – blended with milk or coconut cream to a consistency you can manage*
- *banana smoothie made with soy milk*
- *runny custard (using Ensure® in the milk plus eggs and vanilla or custard powder)*
- *hummus \* (home-made by blending tinned chickpeas and adding olive oil (or similar – see ‘oils’ below) , lemon juice, crushed garlic, salt and pepper, sesame oil or tahini paste\*)*
- *quinoa - use instead of rice – can add savoury or sweet ingredients (a bit ‘cloggy’ so be careful). Amaranth is an alternative with a finer texture.*
- *Oats porridge (see ‘oils’ below)*
- *Pronutro® is an instant porridge from South Africa – see the gluten free section of New World. It comes in several flavours and is soya based. Mix it with cold milk and, since it swells up a lot, let it stand for several minutes. Keep adding milk until it’s a consistency you can manage easily, otherwise it may clog.*

- *frozen minted pea/ broad bean / tinned asparagus puree*
- *mashed avocado and cream cheese\**
- *seedless green grapes, blended*
- *spinach/ silverbeet / broccoli steamed and blended with cheese sauce*
- *parsley/ watercress/ rocket soup (with leek/ onion and potato base)*
- *basil pesto and cottage cheese\**
- *grated cucumber with natural yoghurt, garlic and fresh mint*



- *blueberry smoothie*



- *Beetroot, apple and carrot juice with fresh ginger*
- *cooked beetroot cubed and blended with hummus\* (see above)*
- *juice made with apples, red cabbage, cucumber and a few sprigs of fresh mint*
- *blackberry/boysenberry smoothie*
- *roasted aubergine (seasoned and drizzled with olive oil), blended*



- *very dark chocolate (70%) – when solids are tricky to eat let it melt in your mouth or grate and heat with butter and brown sugar as a sauce to pour over ice-cream*
- *tinned brown lentils, blended and seasoned*
- *mushrooms, sautéed in butter, blended with cream*
- *Maltabella® is a malted sorghum porridge available in South African section of supermarkets*
- *Aria Farm lamb or beef strips (found in frozen section of supermarkets)*



- *Mashed potato (with extra cream/ butter/ cheese and/or herbs, garlic, etc.)*
- *creamed rice, blended*
- *leek/onion and potato soup (can add lots of fresh parsley, blend well)*
- *cauliflower cheese, blended*
- *poached white fish in cheese sauce, blended*
- *maize (mealie) meal porridge – available in South African section of supermarkets (instructions for cooking are on the packaging)*
- *popcorn – preferably the unflavoured sort just add a bit of salt*



## **Drinks**

*Drinking plenty of fluids helps to prevent constipation and maintain healthy kidney function. This is especially important if you are receiving chemo.*

- *Green and white teas are rich in anti-oxidants so in theory may interfere with chemotherapy but only if consumed in large quantities. The same applies to rooibos tea (South African red bush tea – Freshpak brand is a good one) – have with or without milk. Regular (black) tea is good for you too – make iced tea and add honey, fruit slices and a sprig of fresh mint.*
- *Apple cider vinegar and manuka honey (about a teaspoon of each) in a mug of hot water. Try fresh ginger or lemon slices instead of the vinegar.*
- *Mint leaves steeped in hot water.*
- *Miso soup (Asian shops sell the paste in strips of little sachets - just add hot water). For extra nutritional value and flavour you can add cubes of tofu\* (also from Asian shops, kept in the fridges), grated carrot, chopped spring onions, dried shiitake mushrooms, dried seaweed, fresh garlic and ginger, etc. Just sip the broth if you can't manage the solids.*
- *Ensure®/ Fortisip® or Sustagen® powders as needed depending on other food intake. If they taste too rich mixed into milk try them in water (with or without ice). If the bubbles cause you discomfort, add Infacol Drops® (simethicone) to reduce them. (This is usually used for colic in babies).*
- *For a pleasant change occasionally, dissolve a teaspoon of instant coffee powder/ Milo®/ Horlicks® in a dash of boiling water and top up with cold milk fortified with your supplement powder. (Especially nice with a blob of your favourite ice-cream floating in it.)*

## **Oils**

- *Hemp seed oil has a pleasant nutty taste and is a rich source of Omega 3 and Omega 6. Available at the Tamahere Market (3<sup>rd</sup> Saturdays).*
- *Flaxseed (also known as linseed) oil is a good source of omega 3 (the taste takes a bit of getting used to).*
- *Fish oil (Omega 3-D by Nordic Naturals has a lemony taste that is more pleasant than the price).*

*The oils above are best stored in the fridge. Heating will destroy their nutritional value so don't use them for frying. Take a teaspoon or two daily or add a little to smoothies, purees or cottage cheese \* (when you can tolerate the lumps). Apart from their many nutritional properties they soothe a tender oesophagus and act as a lubricant (take at bedtime to lessen the painful 'stickiness' of your oesophagus that can occur, especially at night, during treatment). They may have a gentle laxative action. Oils extracted from olives, avocado, wheat germ, walnut, grape seed, safflower, etc. are all worth investigating and including in your diet according to your preferences, nutritional needs and budget. Choose cold-pressed, extra virgin varieties.*

- *Coconut oil (Ceres does a nice one that is deodorised and organic) is solid at room temperature and can be heated to high temperatures without losing its nutritional value. It's lovely on oats porridge along with brown sugar, cream, raisins, cinnamon, sunflower and sesame seeds, ground almonds, wheat germ, ground linseed ... what happened to the oats? Blend mixture as much as you need to.*



## ***Special spread'***

*As well as being a good source of nutrients and calories this mixture has a gentle laxative action:*

*Roughly chop a selection of dried fruit (raisins/sultanas, dates, prunes, apricots, etc.)*

*Simmer for a few minutes in very little water or green tea.*

*Allow to cool, then add brown sugar and lemon juice (optional).*

*Blend into a thick paste which you can use as a jam or to stir through custard or natural yoghurt.*

*Keep in the freezer – it doesn't solidify.*

## ***My favourite pasta dish***

*Steam chunks of pumpkin/ butternut/ orange kumara or a mixture of the three*

*Add to cooked pasta with pine nuts/ chopped walnuts/ sunflower seeds or a mixture*

*chopped basil/ parsley or a mixture*

*flaxseed/ hemp seed/ olive/ safflower oil*

*evaporated milk (you could add Ensure®)*

*Blend as much as you need to.*

## ***Supplements***

*Everyone will have a suggestion of something 'miraculous' that you should be taking. Very few are clinically beneficial and some may even prevent your treatment from working properly. Research them carefully for safety and efficacy before you part with your cash (see book list below). Discuss with your oncologist, pharmacist and dietician everything you consider using and listen to their advice. If you agree that a product will be of benefit to you then choose a reputable brand and stick to recommended doses. Some people think that "more is better" but often it is not. Tablets and capsules are difficult, if not impossible, to take at certain times and, because the crushed versions often taste hideous, your choices are more limited than most people's. These are a few that might be worth considering:*

- *Vitamins and minerals – Floradix® is a palatable liquid preparation that doesn't burn too much (like iron syrup does!) – available in supermarkets*
- *\* Probiotic – Reuteri® for example – available at health shops and pharmacies. Store in the fridge. Capsules can be opened and the tasteless powder sprinkled on food. Stop using this during chemo treatment as it contains live bacteria and safety has not been established.*
- *Spirulina is a source of many nutrients. The powdered form can be added to juice or smoothies but tablets are more palatable when you are able to swallow them.*
- *Wheat grass/ barley grass powder is gluten free and a source of many nutrients. Mix a teaspoonful with a little water and sugar or honey.*

*\* Avoid these foods when your white blood cell count is low i.e. your immune system's ability to fight infection is reduced. See the booklet from the dieticians on food safety when you have low immunity and the Foodsmart link below.*

## **Other physical aspects**

- *Have a dental check-up as soon as possible after diagnosis. The chemo drugs may cause mucositis (an inflammation of the mucous membranes) which can mean your mouth becomes too sore to brush or floss your teeth properly. Undetected problems could flare up when you least need them to, especially as your immune system may be struggling. Have any necessary dental work done prior to treatment starting if possible.*
- *Mucositis may present as sinusitis-like symptoms, swollen gums, nose bleeds or tenderness at the back of the neck around day 5 of chemo. When you are being admitted to the ward for your first round of chemo it pays to ask for 'mouth care products' to be charted (but not supplied) so that if you need them the hospital pharmacy can supply them without delay. These products are Rivacol Mouthwash® (chlorhexidine), Fungilin Lozenges® (amphotericin) and Nilstat Oral Drops® (nystatin). Ask your nurse to order them at the first sign of trouble. In addition, a gargle of salt (½tsp) and bicarbonate of soda (½tsp) dissolved in a glass of water is quite soothing and has an antiseptic effect.*
- *Diffiam Solution® (benzydamine hydrochloride) is partly funded on prescription and is an alternative mouthwash you might want to consider although it only treats the pain of inflammation and is not antiseptic. It does not contain chlorhexidine so it won't stain your teeth (Diffiam-C, the pink one, does though). This staining is harmless and can be dealt with by your dentist when your treatment is behind you.*
- *A soft toothbrush will be gentle on tender gums.*
- *If mucositis makes you sneeze avoid drinking beetroot juice.*
- *The oncology pharmacists are fabulous people and have a wealth of valuable information about your medication and more – make sure you meet them on their ward rounds.*
- *If you develop oral thrush get antifungal drugs prescribed sooner rather than later – it probably won't self-resolve if your immune system is struggling. Diflucan® (fluconazole) is available as a palatable oral suspension – the contents of the capsules are pretty nasty!*
- *Prompt action is also needed in reporting and treating any other signs of infection that you might be tempted to leave; especially fever, but even athlete's foot or cystitis (bladder inflammation) for example.*
- *Your paracetamol dose in suspension form makes a good 'carrier' or suspending agent for other medications that need to be crushed or emptied out of capsules (e.g. omeprazole – which can be formulated into a liquid preparation for you but needs much bravery to face). Keep track of what you've taken (a chart is handy) and take no more than 4 grams of paracetamol in 24 hours (i.e. take 20ml of the 250mg/5ml suspension no more than 4 times in 24 hours).*
- *Take your prescribed medications for nausea, such as Motilium® (domperidone – not dom perignon, sadly) and ondansetron regularly while on chemo and for several days afterwards. At this time it pays to take them even if you are not feeling nauseous when they are due – they do help you to face food and do the important job of eating. If you find that ondansetron causes constipation, stop that first by decreasing the number of doses per day.*
- *Elizabeth Arden 8 hour Cream Skin Protectant® is wonderful for sore lips. (Not the lip product they also make – the one you want is an orangey colour. It has a strange smell, but you get used to it).*

- *Hospital can be a noisy place so you may find it easier to sleep with ear plugs. Eye shades (from your last flight) help too. If necessary, a sleeping tablet such as zopiclone could be prescribed.*
- *A pack of fragrance-free wet wipes is very handy to have in hospital.*
- *A narrowed oesophagus may mean that when you're lying down saliva doesn't drain the way the way it should and you end up with a horrid wet pillow. To protect it wrap your pillow in a towel or slide one inside the pillow case, both of which can be easily washed.*
- *If you have chemo you will be referred to Hair Creations ([www.wigs.co.nz](http://www.wigs.co.nz)) and have funding of \$400 made available to you. However, don't rush into buying a wig - you may not need one as the chemo drugs commonly used for oesophageal cancer are cisplatin and 5-fluorouracil (also called 5-FU) and these cause only partial hair loss (alopecia). When there seems to be hair everywhere you look and 'shower mice' that get bigger by the day it's sometimes hard to believe that there will be any left on your head. Hair Creations also have a lovely range of turbans and scarves.*
- *A PICC (Peripherally Inserted Central Catheter) is an intravenous line that is usually inserted into a vein in your upper arm, follows the vein over your shoulder and is positioned using x-ray so that it will deliver your medication into a large blood vessel. It can remain in situ for the duration of your treatment and for several weeks afterwards. The doctors will weigh up the risks and benefits and will probably not consider a PICC for your first round of chemo. The biggest plus from a patient's perspective is that you can go home after receiving the first chemo drug (cisplatin) since the second drug (5-FU) can be given via a pump carried in a bumbag around your waist. The pump is driven by the heat of your body. District nurses manage the PICC on home visits.*
- *If smaller veins in your hands are used for IV access they can sometimes develop phlebitis (painful inflammation). This can be relieved by applying Voltaren Gel® (diclofenac). Hirudoid Cream® (heparinoid) may also help.*
- *Once you've got the treatment behind you, take the opportunity to attend one of the monthly "Look Good Feel Better" sessions. You'll meet amazing people and come away looking gorgeous and laden with cosmetic gifts.*
- *Make use of the \$10 massages at The Cancer Society's Lions Lodge, Tainui Street, Hamilton (Ph: 07 8342351 for bookings).*
- *Elizabeth Anne's Baby Shampoo® (available from South African shops) applied as a lotion helps to soothe skin that's feeling a bit rough after radiotherapy is completed (best not to use it during treatment). Aqueous cream is often recommended but it can cause a spotty rash.*
- *If your white blood counts are low so is your immunity. Therefore it is wise to avoid public places like supermarkets (see suggestion below) and movie theatres whenever possible (although the latter are quite empty at 9am). Wash your hands often, change hand towels daily and place an alcohol-based gel dispenser in a central spot at home.*
- *At times when you aren't managing to eat/ drink much, despite your best efforts, conserve energy, i.e. don't burn calories by rushing around unnecessarily - rest when you need to - preferably in a pleasant sunny spot with plenty of fresh air. Allow people to help you. Set boundaries and be discerning about how and with whom you spend your time.*
- *When you are managing to eat/drink a reasonable amount, some exercise will be good for you and helps you to feel better.*
- *Your finger and toe nails may become discoloured and develop a ridge for each round of chemo. This is temporary as they grow out eventually.*

## *Your Mind - mental wellbeing*

- *There can be weeks, or even months, between your diagnosis and treatment starting. This can feel like a frustratingly long time but remember that you have probably had cancer for several years without knowing it. You can choose to use the time wisely to get yourself ready on all fronts.*
- *When possible, stick to your reassuring routines but unclutter your schedule as much as you can, as soon as you can. Delegate your responsibilities and 'tie up loose ends' so that you can focus properly on your health over the months ahead.*
- *You may suddenly find yourself with many questions that need answering. The members of your health care team will be happy to help when you ask them, but there is also much you can do to equip yourself with information that will help you to make decisions based on a clear understanding of your disease and your treatment options. The list of websites and books below is a good starting point, as are the Cancer Society liaison nurses (Phone 07 8382027 or 0800 226237 to find out who is covering your area).*
- *Get accurate staging (even if it means enduring more tests) so that your research of the treatment options can be more focussed. If you can't face the research yourself ask someone (or several people) whom you trust, and who have the necessary skills, to help you.*
- *Get a file with dividers to sort and store information, documents, reports, etc. in a tidy, logical way so that you can find them easily.*
- *Start a list of what people say they can do to help and when they are available. You may not be able to rely on your memory as much as usual.*
- *Compile rosters if you need them e.g. for transport for yourself (to and from tests, gastroscopies or radiotherapy) and for other family members who would normally be relying on you for transport.*
- *Consider setting up an online alternative for your grocery shopping so that it's there if you need it. Countdown offers this option but watch the delivery fees (their operation is run from the Westfield Chartwell store). You can collect your order but perishables will not be included in this case. You may already have a Onecard which can be used to set up a shopping list based on your recent purchases. ([www.countdown.co.nz](http://www.countdown.co.nz))*
- *If you want a preview of the radiotherapy process or a way of sharing your experience with interested family and friends visit [www.waikatodhb.nz/page/pageid/2145844561#radiation](http://www.waikatodhb.nz/page/pageid/2145844561#radiation) and click on "See a linear accelerator in action" (below the third picture). There have been a few improvements made to the department and the groovy gowns since this was filmed.*

## Useful websites and books

The internet can be an alarming place but here are a few reputable sites where you can find support and reliable information:

New Zealand Cancer Society – [www.cancernz.org.nz](http://www.cancernz.org.nz) / [www.cancersociety.org.nz](http://www.cancersociety.org.nz)  
(includes CancerChat and CancerConnect)

New Zealand Food Safety Authority –

[www.foodsmart.govt.nz/elibrary/lowimmunity.pdf](http://www.foodsmart.govt.nz/elibrary/lowimmunity.pdf)

Cancer Council Australia – [www.cancer.org.au](http://www.cancer.org.au)

Peter MacCullum Centre – [www.petermac.org](http://www.petermac.org)

American Cancer Society – [www.cancer.org](http://www.cancer.org)

National Cancer Institute (US) – [www.cancer.gov](http://www.cancer.gov)

American Institute for Cancer Research – [www.aicr.org](http://www.aicr.org)

(includes New American Plate)

NCCN (National Comprehensive Cancer Network - US) – [www.nccn.org](http://www.nccn.org)

Macmillan Cancer Support (UK) – [www.macmillan.org.uk](http://www.macmillan.org.uk) or

[www.cancerbacup.org.uk](http://www.cancerbacup.org.uk)

Smart Patients ([www.smartpatients.com](http://www.smartpatients.com))

Bravenet (website/ blog builder) – [www.bravenet.com](http://www.bravenet.com)

Hair Creations – [www.wigs.co.nz](http://www.wigs.co.nz)

Countdown – [www.countdown.co.nz](http://www.countdown.co.nz)

Healthy Food Guide magazine – [www.healthyfood.co.nz](http://www.healthyfood.co.nz)

There are literally hundreds of relevant books available but here are a few suggestions as a place to start – each will have recommended reading lists that can take you on an exciting voyage of discovery.

- “Cancer: a threat to your life or a chance to take control of your future”  
by Dr Monica Lewis and Dr Gerald Lewis
- “Life, Happiness...and Cancer”  
by Phil Kerlake
- “The new complete guide to nutritional health: more than 600 foods and recipes for overcoming illness and boosting your immunity”  
by Pierre Jean Cousin and Kirsten Hartvig
- “Complementary therapies for cancer: what works what doesn’t and how to tell the difference”  
by Shaun Holt

All of the above are available from Hamilton City Libraries.

- “When a parent has cancer: a guide to caring for your children”  
by Dr Wendy Harpham

Available on Library Interloan system from Wanganui Library (\$5 fee) but Rainbow Place on Cobham Drive has a copy.

## *Your Feelings – emotional wellbeing*

- *Take your favourite uplifting music to hospital along with some photos or inspiring quotes for your notice board. If your hobbies aren't suited to a hospital ward, get some books about them out of the library (and take a notebook to jot down all the ideas you'll get for future projects). Modern technology could, of course, meet all these needs with one device.*
- *There is a piano in the lounge on the oncology ward which you, or one of your visitors, might like to put to good use – it will give everyone a lift (provided sessions are short and you don't practise scales when you can't sleep at night).*
- *Even in hospital, the effort of getting up, showered and dressed is worth it for the sense of normality and control that it gives you (although one sleeve will prove tricky when the IV is attached to your hand).*
- *Try to sit in a chair some of the time, not always on the bed.*
- *Take a snuggly rug or blanket to hospital with you.*
- *Drip stands need a bit of cheering up. See what you can find to hang on yours (that won't get in the way or make a noise when you're on the move).*
- *Don't be shocked if people enter your hospital room from what you thought was a private en suite bathroom – you may be sharing it with the occupant of next room and their visitors might use it as an escape route.*
- *New pyjamas, a dressing gown or slippers (or all three if you're lucky!) are a lovely treat and help you to feel presentable even when people pop in before you've found the energy it takes to have that shower.*
- *Singlet tops with built in bra support are a wonderful invention and worth treating yourself to for hospital stays, especially as they are comfortable enough to sleep in.*
- *If you have pets they will probably sense that something is wrong and may become more attentive as a result. They can provide wonderful company and be a huge source of comfort (but be conscious of hygiene and sensible about washing your hands before handling food, not allowing them to lick your face, etc.)*
- *When eating in public places embarrassment can be avoided by checking out the exact location of the restrooms before your meal arrives. That way if you were too ambitious about what you thought you could eat (while also having a conversation) and food does get stuck, you don't end up in the cleaners' cupboard (despite following the restroom signs).*
- *It's horrid to feel left out and hungry when dining out with friends so plan ahead and call the restaurant to see if they can accommodate your needs. If their soups are either a spicy Thai, acidic tomato or chunky chowder they may be happy for you to bring along something you can eat in a microwave-proof dish that can be warmed up for you. Most places will be happy to oblige especially if you assure them that you will be buying a big hot chocolate or milkshake for dessert.*
- *Discover which relaxation techniques work for you – breathing exercises, guided imagery, meditation and prayer may all be helpful.*
- *Enjoy having time to watch a bee in a flower or a bird building a nest (with the hair you gathered around the house and put out for them).*
- *Hire funny movies and have a good laugh with those you love.*
- *Be kind to yourself and take comfort in knowing that you're doing the best you can when you can.*

## *Your Community - social wellbeing*

- *Contact the New Zealand Cancer Society (07 838 2027 or 0800 226237 see the website) and ask to be put in touch with the liaison nurse for your area. She will inform you of all the services available to you.*
- *Once your family and friends hear of your diagnosis they are likely to phone or visit which can be overwhelming. If you need your space put the word out that you would prefer not to have visitors at the moment – it's easier to 'open the door' a bit later than to close it. If you feel that this seems selfish or rude coming from you, then perhaps a family member, a close friend or your boss would do it on your behalf. People tend to be very understanding and respectful of your needs at this time.*
- *You might want to get an answer phone with caller ID.*
- *Consider starting an internet blog (see 'Bravenet' in the list of websites above or choose another provider) – it's easier than you think and keeps all concerned parties informed, stops the phone and doorbell ringing and allows you to rest, eat and think straight when you need to the most. Ask someone else to set it up and maintain it for you if that part is a problem. You can pay an annual fee if you want password access for privacy (about \$50). Send the internet link via email or text to all those who might want to keep up with your news.*
- *These are not normal times and, as hard as it might feel, it is essential to focus more on yourself and your needs than you might usually. Be intentional about having those needs met so that you can do the work of getting well again. Self-care is not selfish. Learn to feel comfortable about saying 'no' to things that you would normally take on. Friends and family will want to help you but don't always know how to, so be specific and draw on the strengths and interests of those around you by asking them to cook, bake, shop for groceries (or collect your online order), provide transport, weed your garden, rake the leaves, wash your windows, clean your car, vacuum and mop the floors, clean out the fridge, do your laundry, give you a back rub, walk the dog, etc. ... your enjoyment of their support will give them much pleasure. It can feel overwhelming to be at the centre of so much attention and care but remember that if you spread the load each person is only doing their bit. Allow them to heal you from different angles in the same cumulative way that the doses of radiotherapy do.*
- *A roster for rides to radiotherapy creates a lovely opportunity to spend some one-on-one time with a different family member or friend each day.*
- *The fortnight following a 28 dose radiotherapy programme can coincide with the third round of chemo and tends to be a tough patch, so it may be worth planning for some extra support around that time.*
- *The hospital visiting hours are not strictly adhered to on the oncology ward but the nurses will put a sign on your door if you need to rest.*
- *Rainbow Place on Cobham Drive has wonderful staff and resources to support children dealing with cancer in their family.*
- *Expect to meet many wonderful people in the weeks ahead – some of them will be caring for you, others will be receiving care alongside you.*
- *A concessional parking card is available for the hospital – the receptionists at Oncology Outpatients will give you a form to take to the Wilson Parking building nearby. At \$1/day it could save you a lot especially during radiotherapy treatment when you are there every day.*

## *Your Soul – spiritual wellbeing*

- *Look after your spiritual needs in ways that are meaningful and suit you best.*
- *While you're resting and eating you can be caring for your spiritual health at the same time by reading, listening to music and podcasts or watching DVDs of your favourite preachers and teachers.*
- *Look for the purpose in your present situation and be aware of opportunities to learn and grow in various dimensions.*

### ***My favourite sayings and quotations***

*If you can't see the bright side of life then polish the dull side.*

*Proper Preparation Prevents Poor Performance*

*Bloom where you are planted (even on an oncology ward)*

*It's not the destination but the journey you take to get there that's important.*

*Do your best and watch God do the rest.*

*Faith is the bird that feels the light and sings though the dawn is still dark.*

*Don't strain and pull or drag your heels, just let go and let God.*

*Life isn't about how to survive the storm, but how to dance in the rain.*

*Rather than questioning the purposes of God, seek His presence.*

*No rain; no rainbows.*

*Life is a sexually transmitted disease with a 100% mortality rate.*

*Smooth seas do not make skilful sailors.*

*African Proverb*

*"Science without religion is lame; religion without science is blind"*

*Albert Einstein*

*"I encourage my patients to have faith in God but not to expect Him to do all the work."*

*Dr. Bernie Siegel*

*"We cannot do God's part and He will not do ours."*

*Joyce Meyer*

*"Have courage for the great sorrows in life and patience for the small ones. And when you have laboriously accomplished your daily tasks, go to sleep in peace; God is awake."*

*Victor Hugo*

*"We can use any tragedy as a stumbling block or a stepping stone."*

*Glyn Johnson*



*"Life goes on even when things don't go according to plan."*

*Dr. Richard Carlson*

*"Whether you think you can or you can't, you're usually right."*

*Henry Ford*

*"Hope is not the conviction that something will turn out well, but the certainty that something makes sense regardless of how it turns out."*

*Václav Havel*

*"Courage doesn't always roar. Sometimes courage is the quiet voice at the end of the day saying 'I will try again tomorrow'."*

*Mary Anne Radmacher*

*"Finish each day and be done with it. You have done what you could. Some blunders and absurdities have no doubt crept in; forget them as soon as you can. Tomorrow is a new day; begin it well and serenely and with too high a spirit to be encumbered with your old nonsense."*

*Ralph Waldo Emerson*

*"Courage is resistance to fear, mastery of fear - not absence of fear."*

*Mark Twain*

*"It is in the quiet crucible of your personal private sufferings that your noblest dreams are born and God's greatest gifts are given in compensation for what you have been through."*

*Whintley Phipps*

*"We are doing the best we can with the understanding, awareness and knowledge we have. As we gain more understanding, awareness and knowledge then we will do things differently."*

*Louise Hay*

*(in "You can heal your life.")*

*"The important thing about your lot in life is whether you use it for parking or building."*

*Lee Ezell*

*"What is this cheerfulness that dares to wink at adversity? What is this source of peace that defies pain? I call it sacred delight."*

*Max Lucado*

*"I can't be powerful if I am pitiful."*

*Joyce Meyer*

*"If I wake up and see the ceiling I know two things: I'm alive and I'm not blind!"*

*David Whitburn*

*"The mind is its own place, and in itself can make a heaven of hell, a hell of heaven."*

*John Milton, poet.*

*"Happiness depends upon ourselves."*

*Aristotle*

*"People are not disturbed by things, but by the view they take of them."*

*Epictetus, 1st century AD*

*"Most people are as happy as they make up their minds to be."*

*Abraham Lincoln*

*"Life is available only in the present moment. Happiness can only be possible in the here and now."*

*Buddha*

*"Our lives are not determined by what happens to us but by how we react to what happens, not by what life brings to us but by the attitude we bring to life. A positive attitude causes a chain reaction of positive thoughts, events and outcomes. It is a catalyst, a spark that creates extraordinary results."*

*Anonymous*

*"Don't aim to stay alive, but to live!"*

*Living Legacies website*

*"We need to enjoy where we are, while we are on our way to where we are going."*

*Joyce Meyer*

*"You create your own life. You create your own happiness. You make the choice whether you are happy or unhappy. It is not the circumstances that force the happiness or unhappiness upon you. You determine your own emotional health. You determine your perceptions of the events that occur to you, and it's up to you to make them into positive emotions."*

*Montel Williams*

*(in "Living well emotionally")*

*"Eight habits of happy people:*

*Deeply enjoy and nurture relationships with family and friends*

*Be grateful for everything life offers*

*Think positively and optimistically about life events and about the future*

*Commit strongly to life goals*

*Be generous and forgiving with other people*

*Be self-confident and resilient in the face of stress and tragedy*

*Savour life's pleasures and live 'in the moment'*

*Be physically active on a regular basis (every day)."*

*Montel Williams*

*"It is not that someone else is preventing you from living happily; you yourself do not know what you want. Rather than admit this, you pretend that someone is keeping you from exercising your liberty. Who is this? It is yourself."*

*Thomas Merton*

*"I know God will not give me anything I can't handle. I just wish He didn't trust me so much!"*

*Mother Theresa*

*"Do all the good you can  
By all the means you can  
In all the ways you can  
At all the times you can  
To all the people you can."*

*John Wesley*

*"Love cures people – both the ones who give it and the ones who receive it."*

*Dr. Karl Menninger*

*"Let your enthusiasm radiate in your voice, your actions, your facial expressions, your personality, the words you use and the thoughts you think."  
Ralph Waldo Emerson*

*"Thank you, God, that Your Son has set us free! The yoke of cancer is temporary, but the yoke of slavery to sin is permanent without Jesus."  
Yvonne Ortega*

*"Personal responsibility for health means refusing to be a victim. It means participation in recovery by recognising and changing self-destructive beliefs and behaviour. This means believing I am in charge of my cancer; my cancer is not in charge of me."  
Greg Anderson*

*"We need to have a great respect for ourselves and a gratitude for the miracle of our bodies and our minds."  
Louise Hay*

*"Today is all you ever had; tomorrow was always in question."  
Phil Kerslake*

*"Experience is not what happens to a man; it is what a man does with what happens to him."  
Aldous Huxley*

*"I learnt that my sense of being is not dependent on what I do. I learnt the essential value of doing nothing."  
Sheila Slattery, Cancer Chat*

### **What Cancer cannot do**

*"Cancer is so limited...  
It cannot cripple love.  
It cannot shatter hope.  
It cannot corrode faith.  
It cannot destroy peace.  
It cannot kill friendship.  
It cannot suppress memories.  
It cannot silence courage.  
It cannot invade the soul.  
It cannot steal eternal life.  
It cannot conquer the spirit."*

*Lee Ezell*

### **The Tapestry**

*"My life is but a weaving between my Lord and me.  
I cannot choose the colours, He worketh steadily.  
Oft' times He weaveth sorrow and I in foolish pride  
Forget He sees the upper, and I the underside.  
Not 'til the loom is silent and the shuttles cease to fly  
Shall God unroll the canvas and explain the reason why  
The dark threads are as needful in the Weaver's skilful hand  
As the threads of gold and silver in the pattern He has planned."  
Annie Chapman*

### **Serenity Prayer**

*“God, grant me the serenity to accept the things I cannot change;  
courage to change the things I can;  
and wisdom to know the difference.  
Living one day at a time;  
enjoying one moment at a time;  
accepting hardships as the pathway to peace;  
taking as Jesus did, this sinful world  
as it is, not as I would have it.  
Trusting that you will make all things right  
If I surrender to Your will;  
That I may be reasonably happy in this life  
and supremely happy with You  
forever in the next.  
Amen.”*

*Reinhold Niebuhr*

### **The Best Philosophy**

*“Take the bitter with the sweet,  
The laughter with the pain,  
Take the rough with the smooth,  
The sunshine with the rain.  
Life is not all happiness and life is not all sad.  
The mixture of the two, the good things and the bad,  
So learn to take without complaint,  
Whatever fate may give.  
That's the best philosophy and that's the way to live.  
Not to ask too much from life,  
But be grateful if you're blessed,  
Always ready for the worst,  
But always hoping for the best.”*

*NZ Cancer Society*

### **Extravagant Love**

*“To be alive this day – this is your gift to me!  
To breathe and stretch and yawn – this is your life in me!  
To step into this day with you at my side – this is your faith in me!  
Your presence fills the universe yet you choose to lodge here within me.  
You are beyond my wildest imaginings yet you are closer than my own breath.  
I know you in the smile of the stranger, in the tear of a child,  
Yet you are as elusive as the wave on the shore.  
God of mystery and delight,  
God of tenderness and longing,  
nurture your life within me, that I may be free in you.*

*In the moments when I don't know where to turn and forget that you are my  
pole star, help me to turn to you.  
In the moments when I am lonely and forget that you are my companion, help  
me to remember that you are beside me.  
In the moments when I weep and forget that your eyes glisten with tears, help  
me to sense your sharing in the pain.*

*In the moments when my friends surround me and I fail to see your image reflected, help me to see you in their eyes.  
In the moments when I laugh yet fail to trust the music in my soul, help me to hear the echo of your life within me.  
In all of these moments, strange and joyful, beautiful and challenging, happy and despairing, help me to remember your presence.  
So taken up with all we must do, all we must be, all we must achieve, we pray, dear Lord, for ourselves in all our complexity; teach us to stop and stare; to stand empty-handed before you; to drink deeply from the well of your love and to know ourselves accepted.”*  
from “A liturgy for corporate prayer in the morning.”

### ***A Recipe for Wellness***

*Take a cup of relaxation,  
Some sensible advice,  
An optimistic attitude,  
And sift them once or twice.*

*Then measure in some sunshine,  
Add a visitor or two.  
Flavour with some happy thoughts  
And quiet things to do.*

*Keep covered very carefully,  
Stir only now and then.  
(Be careful - if you stir too much  
You'll have to start again!)*

*Warm slowly in a cosy place.  
Let rest for just a spell  
And serve with all the happiness  
that comes from being well.*

*Sure hope you'll try this recipe  
And hope it works out too,  
'Cause if anyone deserves good health  
It's someone just like you!*

## ***My favourite Bible verses***

***God promises us His peace, presence, provision, protection and power.***

*"Faith is the assurance of things hoped for, the conviction of things not seen."  
Hebrews 11:1*

*"We live by faith not sight."  
2 Cor 5:7*

*"My father, if it is possible may this cup be taken from me. Yet not as I will but as You will."  
Matt 26:39*

*"We are hard pressed on every side, but not crushed; perplexed, but not in despair; persecuted, but not abandoned; struck down, but not destroyed. Therefore do not lose heart. Though outwardly we are wasting away, yet inwardly we are being renewed day by day. For our light and momentary troubles are achieving for us an eternal glory that far outweighs them all. So we fix our eyes not on what is seen, but on what is unseen. For what is seen is temporary, but what is unseen is eternal."*

*2 Cor 4: 8-9, 16-18*

*"Do not fear for I am with you; do not be dismayed for I am your God. I will strengthen you and help you; I will uphold you with my righteous right hand."  
Isaiah 41:10*

*"God is faithful. He never leaves us nor forsakes us. He neither slumbers nor sleeps."  
Psalm 121:4*

*"And surely I will be with you always, to the very end of the age."  
Matt: 28:20*

*"The Lord your God goes with you. He will never leave you nor forsake you."  
Deut 31:6*

*"Be strong and courageous! Do not tremble or be dismayed, for the Lord your God is with you wherever you go."  
Joshua 1:9*

*"God is our refuge and strength, an ever-present help in trouble. Therefore we will not fear."  
Psalm 46:1*

*"He alone is my rock and my salvation; He is my fortress, I will not be shaken."  
Psalm 62:6*

*"My grace is sufficient for you, my power is made perfect in your weakness."  
2 Cor 12: 9-10*

*"Who of you by worrying can add a single hour to his life?"  
Matt 6:27*

*"Do not be anxious about anything, but in everything, by prayer and petition, with thanksgiving, present your requests to God. And the peace of God which transcends all understanding, will guard your hearts and minds in Christ Jesus."  
Phil 4:6*

*“Trust in the Lord with all your heart and lean not on your own understanding. In all your ways acknowledge him and he will make your paths straight.”*

*Prov 3:5*

*“Peace I leave with you; my peace I give you. I do not give to you as the world gives. Do not let your hearts be troubled and do not be afraid.”*

*John 14:27*

*God gives “beauty instead of ashes, the oil of gladness instead of mourning, and a garment of praise instead of a spirit of despair.”*

*Isaiah: 61:3*

*“Weeping may remain for a night, but rejoicing comes in the morning.”*

*Psalms 30:5b*

*“The steadfast love of the Lord never ceases, his mercies never come to an end. They are new every morning; great is Your faithfulness.”*

*Lamentations 3:22, 23*

*“God heals the broken-hearted and binds up their wounds.”*

*Psalms 147:3*

*“Who shall separate us from the love of Christ? Shall trouble or hardship or persecution or famine or nakedness or danger or sword? As it is written: ‘For your sake we face death all day long; we are considered as sheep to be slaughtered.’ No, in all these things we are more than conquerors through Him who loves us. For I am convinced that neither death nor life, neither angels nor demons, neither the present or the future nor any powers, neither height nor depth, nor anything else in all creation will be able to separate us from the love of God that is in Christ Jesus our Lord.”*

*Romans 8:35–39*

*“I can do all things through Christ who strengthens me.”*

*Phil 4:13*

*“She is clothed with strength and dignity, and she laughs without fear of the future.”*

*Proverbs 31:25*

*“Those who hope in the Lord will renew their strength. They will soar on wings like eagles; they will run and not grow weary, they will walk and not be faint.”*

*Isaiah 40:31*

*“This is the day that the Lord has made, we will rejoice and be glad in it.”*

*Psalms 118:24*

*“The Lord is my shepherd, I shall not want.”*

*Psalms 23: 1*

*“Be still and know that I am God.”*

*Psalms 46:10*