

The background of the entire page is a vibrant, abstract collage of hand-drawn shapes and colors. It features various swirls, circles, and organic forms in shades of red, yellow, blue, pink, and black. A prominent red heart shape is visible on the left side, and a brown, multi-layered flower-like pattern is on the right. The overall style is expressive and artistic.

# Living with Myeloma

A personal reflection...

## **About the Author**

Greg O'Donnell has been living with myeloma for the past 19 years, having had smouldering myeloma for 12 years and then active myeloma requiring treatment over the past 7 years. Greg has put pen to paper recently to help out a family friend, who was recently diagnosed with another form of cancer. He felt some of his own cancer experiences and reflections may be helpful to her in some way, and indeed they were.

Greg has kindly agreed to make his reflections available to the wider myeloma community, in the hope that we can all take away something to help us and learn from his experiences.



## Foreword

Having specialised in providing supportive care to those with myeloma for over 15 years I understand the value and comfort people receive in hearing the stories and experiences of others living with myeloma. The power of these shared experiences is not to be underestimated.

Greg reflects on the many things he has learnt during the last 19 years of living with Myeloma. He emphasises that each individual's journey is unique and he does not suggest that *all* of what is included here will be helpful or meaningful to everyone. Rather he very generously shares his own personal 'top tips' that have helped him along the way in the hope that others are able to find something among them that will help them along their way too.

I whole heartedly recommend this sensitive and practical reflection on dealing with the complexities and uncertainties brought about by a diagnosis of myeloma. I will certainly be making it available to those I care for directly with myeloma and have no doubt it will become a useful resource to supplement the information I can provide to my patients. I hope you find it as much of an inspiration as I have found it to be.

### **Tracy King**

Myeloma CNC

RPAH

This collection of 'top tips', from someone who has been through it all, is a wonderful blueprint for how to cope with a life-threatening illness. Greg has used his own experiences to accurately portray the roller-coaster ride that all patients with myeloma and other cancers inevitably go through. While acknowledging that what happens will differ for each individual, Greg addresses fundamental issues that are often overlooked by the professionals involved in the care of patients with cancer, and identifies many helpful strategies that will be useful to all those that read this personal reflection.

I greatly appreciate Greg's efforts in producing this guide, which I will thoroughly recommend to all my patients.

***Harry Iland***

Clinical Haematologist  
Institute of Haematology RPAH

We need to thank Greg for this invaluable guide because he has just made our jobs so much easier! We spend much of our time with patients helping them understand that their reactions and feelings to the cancer experience are completely normal, but nothing quite compares to hearing this from someone who is actually living the journey. Greg has captured the key themes and issues of living with cancer and summarised them in an honest, thoughtful and at times, refreshingly light hearted way (which is very true to his character). His ability to drill down to the most important points amongst a mass of overwhelming, emotion-laden and fraught information will make this guide so useful to so many patients.

Whether you have been newly diagnosed with cancer or you have been living with illness for some time, we encourage you to read this guide. We also encourage you to pass it on to family and friends so they can better understand your inner world and experiences.

***Nicole Ferrar & Toni Lindsay***

Clinical Psychologists  
Psycho-Oncology Service RPAH



You have started on a journey which will be both interesting and daunting. It is your journey and whilst others might be able to give you advice and tips, the ultimate decisions remain solely with you. Others may have gone on similar journeys but this particular one is unique to you.

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On this journey you will discover strengths you did not know you had and be reminded of weaknesses you might wish you did not have. Work to your strengths and work around your weaknesses.

This is a good time for you, yourself to develop the ability to say "no" too!

One strength you will need to develop is to ask for help. In the past you have been there for others, now it is your turn to expect others to be there for you. The worst thing that can happen is that occasionally someone will say no. Speaking of which, this is a good time for you, yourself to develop the ability to say "no" too!

In 2001, Marguerite Lane developed a list of characteristics of survivors of life-threatening illnesses by adapting work done by Margaret Spicer in 1998<sup>1</sup> Survivors:

- Have a sense of personal responsibility for their health
- Have a sense that they could influence their own health (not be a victim)
- Have a commitment to life in terms of unfinished business, unmet goals, unfulfilled wishes...
- Find new meaning and purpose in life as a result of the illness itself
- Engage in some physical activity, exercise & dietary work
- Find useful information & supportive contact with a person with the same diagnosis shortly after their own diagnosis

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<sup>1</sup> Marguerite Lane (2001) Characteristics of Survivors of Live-Threatening Illnesses. Adapted from Margaret Spicer, 1998.

- Become altruistically (unselfishly) involved with other affected persons
- Accept the reality of the diagnosis but refuse to see it as a death sentence
- Develop a means of coping assertively and the ability to say NO!
- Have the ability to withdraw from taxing involvements & nurture themselves
- Are sensitive to their body's physical & psychological needs
- Communicate openly about their concerns
- Have a healing, broad-minded relationship with their primary health care provider

This will present you with a steep learning curve at a time when, in all honesty, the natural tendency is to simply withdraw. Be mindful of Elisabeth Kubler-Ross's five stages of grieving – in many ways you are grieving. These stages are denial, anger, bargaining, depression and finally acceptance. Once you have got to the acceptance stage, you can then get on with the rest of your life.

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So, to look at the positive side, you need to know your enemy and to do this you have to learn as much as you can about it. This will require you to research various sources but that is only half the battle. You then need to have your findings either confirmed or denied. There is no guarantee that all sources actually know what they purport to know. However, you can rank your sources along the following lines:-

1. **Your primary health care provider.** This is their area of expertise so they should be your first port of call either to allay any fears you might have or to confirm or deny any thing you may have been told or read. If they laugh, console yourself with the knowledge that they have either

heard it so many times before or you have managed to bring them something new. There is also the possibility that you have given them something to think about. There are a few things to remember though

- a. In a clinic situation, they might only be allotted about eight and a half minutes to see you. So if you have some concerns, give them prior warning and ask for a longer consultation.
- b. Keep notes, write down any questions before the consultation and record any responses.
- c. It is helpful to take someone with you. A practical reason for this is that if there is any bad news delivered, you might naturally miss any subsequent advice and suggestions.
- d. Monitor your vital signs, particularly your temperature. Like a good vacuum cleaner, you will tend to pick up everything. Get the flu shots. Invest in a good thermometer. When in doubt, seek help. Do not be a martyr. You do not have to turn into a hypochondriac but remember the game has changed and you are playing under new rules.

**2. Additional Health Care Providers – the rest of the team.** Besides the oncologist and radiotherapist (or Registrar/Nurse/Assistant) you will see in clinic there is a whole plethora of people who are charged with your well-being. Get to know them and actively seek them out. This is a team effort and to be blunt, you are simply the ball carrier and your goal is to get that ball over the goal line. You have this team to support you. Do not focus on the ball, focus on the goal line. Members of the team are as follows (they might go by different names or titles at the place you receive treatment so make some enquiries) starting with the:-

- a. **Clinical Nurse Consultant/Specialist.** In some ways, the Clinical Nurse is more important than the primary health care provider as the Clinical Nurse tends to concentrate on you rather than the ball. Ask the Clinical Nurse for information about other members of the team and if you have any particular concerns who would be

the best team member to refer such concerns to. Get their contact number or better still, their email address. Often, it will be a restless night when a question will occur to you. Shoot off an email. You never know, by being that little bit pro-active, you might just take the edge off your concern.

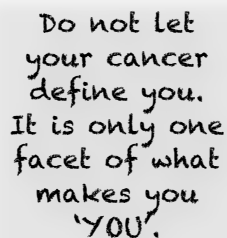
- b. Psycho-oncologist.** Possibly an unfortunate name, but a great source of knowledge. There will be questions that might seem far too mundane or even inane to ask the oncologist or equivalent but squarely fall into the area expertise of the psycho-oncologist. These could include such varied matters as recurrent strange dreams, detected changes in your personality and a myriad of others.
- c. Dietician.** The various treatments you will be receiving will possibly have some strange effects not only on your body but also on your appetite. This may fluctuate from being so hungry you could eat a horse and chase the rider, to getting by on a cup of tea and a stale biscuit. You will need to have a balanced approach as demands may be made on your body that would make a supreme athlete blanch. More notes on diet will follow later in these notes
- d. Welfare.** Being independent to date, you might well baulk at the thought of seeking out the services of a Welfare person. Swallow your pride (a little) and remind yourself that you are not so much seeking a hand-out as identifying ways and means of lightening the load you and your loved ones are carrying. It is just possible that by using some of the Welfare services (e.g. transport) you are actually helping lighten the load of your loved ones.
- e. Your GP.** This list is not necessarily in correct pecking order. Remember that most of the above are approaching you with a certain vested interest, whereas your GP has a more holistic approach and will be treating you for some less more common complaints. Ensure that all the other health care providers attending you keep your GP in the loop so together the two



parties can manage the whole package. Medicine is still in many ways, more an art than a science.

f. **A go-to person.** Preferably someone who has received the same diagnosis as you. Someone who is not judgemental (as you should not be judgemental) and someone who is also more focused on their own goal line and less on the ball. Someone you are at ease with and someone you have virtual complete trust in.

3. **Yourself.** You are still the best judge of what is happening to you. There will be changes, some subtle, others less so. Some gradual, others virtually overnight. Weight gain and loss of or changes to your sense of taste. Note each one and refer them to your health care provider. One good way to keep track of changes is to keep a health journal. As we all get older, more and more parts of each of us go on the blink, different medications will be prescribed – along with possible other vitamins and supplements you might well self-prescribe. Include in your journal not only physical changes, but attitudes, fears and personality changes. You could well find that your likes and dislikes in the people you would rather spend time with, could change. Some of this could be put down to your re-evaluating just what is important and what is not.



Do not let  
your cancer  
define you.  
It is only one  
facet of what  
makes you  
'YOU'.

4. **The Cancer Council.** Cancer is their reason for being and they produce a whole raft of publications. Go to [www.cancerCouncil.com.au](http://www.cancerCouncil.com.au) or ring 13 11 20. Their publications are aimed at helping you and your carers. At times such publications are a great way of keeping your carer on track. After all, you are the one with the cancer. It is your own journey and you have certain rights.

5. **The Web.** A great place to do research but remember that is all it is. Whatever you discover, generally it is important to pass it by, say your Clinical Nurse before you embrace it fully. When checking say a particular drug you have been prescribed, the manufacturer will list

under possible side effects both extremes – which may cover them but is not really helpful to you.

**6. Other people.** In some ways, other people are going to be the greatest challenge that will face you. So you need to set some ground rules. Rules that you will need to apply to yourself as well as rules you will have to enforce on others.

**a. No!** By far the hardest thing you will have to learn. Your prime concern is to look after Number One – you. If that means that on occasions you have to be rude, then be rude. You can always “blame it on the drugs”. People can do strange things when they hear that word “Cancer” so in some ways you are actually helping them. Always keep your sense of humour, it can be the best weapon in your armoury.

**i. Need to know.** Just how much you tell people is up to you. There are some, say your work supervisors who need to know the full story, but others like work colleagues who only need to know the basics. It is your story so you decide just how much you tell various people. And then there are those who really do not need to be told anything. Sometimes it helps to be vague – again blame it “on the drugs”.

**ii. But you look so well.** Usually said when you are feeling like something the cat has dragged in. Perhaps it is their way of being in denial. Best solution is to smile and find someone else to talk to.

**iii. I know of a friend of a friend...** You know immediately that this is not going to end well, so as quickly as possible change not only the subject but the speaker. Suddenly remember a pressing engagement – another thing you can blame on the drugs.

**iv. People are such germ factories.** Especially little people. Your immune system will be shot so you need to take precautions. If someone is obviously on the sick list – avoid them.

**v. Be positive.** It is amazing just how many people come up with this advice. The silly thing is that is precisely just what you are attempting to be – but there will be times when it is well nigh impossible for you to achieve. Do not beat yourself up. Allow yourself time to wallow in some well earned self pity, but set a specific time limit. Tell yourself, okay for the next two hours I am going to huddle here and be miserable but then I am going to make myself a strong cup of tea and get on with the rest of my life.

**b. Some people can actually be beneficial.** If someone makes you feel good, then seek out their company. It might be selfish, but you have an ulterior purpose. What you tell them is up to you. They are there simply to make you feel good, a means of distraction. They could be people associated with a particular activity be it quilting or DIY classes. Whatever floats your boat.

**7. Time out.** Alluded to briefly above, you should find some activity that is in no way cancer related. The fact that you have cancer can be debilitating. There is such a thing as cancer related fatigue (CRF) – see if you can find material on this with the Cancer Council. Pace yourself, set achievable goals, push yourself a little more each day. Acknowledge that there will be some activities that you may not be able to perform as well as you used to. Besides the cancer, you are also getting older. Remember that getting older beats the alternative. You might find new interests.

**a. Religion.** If you were not religious before diagnosis, the possibly any new found religious tendency might not be well grounded. However, if you did have religious tendencies beforehand, you can use any quiet times to peaceful reflection and contemplation and meditation.

**b. Yoga and other relaxation techniques.** Why not? Possible before undertaking any physical exercise regime, it might be advisable to pass it by your health provider.

c. **Volunteering.** Often as not, a bit of volunteering adds a bit of zest to your life. It can at least take your mind off other pressing matters.

d. **Other pursuits.** Particularly ones that stretch the mind. Learn a new skill, a language, acquire a hobby, especially one that you can put down or take up at will. The whole point is to keep the mind active (and at times distracted). Start a collection but one word of warning, choose a collectible that will not prove too expensive in either terms of money, space or demands on time. Keeping the mind and body active may also delay the possible onset of dementia. You have enough on your plate already.

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8. **Diet.** Your body will be undergoing some changes and you need to ensure that you keep it well fed. As said earlier, your appetite can change day by day (as can your weight). You have enough to worry about already so do not add these two to your list. Keep track of both (use your journal) and if it does cause concern, raise it with your health professional.

a. Your taste could be all over the place. You might start off being hungry but by the time the meal has been prepared, you may have lost your appetite. This can be very annoying when dining out – especially if you are paying.

b. One solution is to prepare small servings. Where is it written that we can only have three meals a day. What's wrong with five meals.

c. Your appetite can be shot, as can your sense of taste. Compensate by trying to make your serving look attractive. Mix the colours. Don't settle for bland!

Don't settle for bland!

9. **Outlook.** In many ways you will be playing mind games with yourself. Make it interesting. Be aware that you can easily suffer depression, from mild to severe – from that horrible black dog to a mischievous pup that keeps messing up your garden of tranquility. It is part and parcel of the journey. You need to be aware of where your mind “is at”. That is not to say that every now and then, you can’t give yourself some time off. You don’t have to be in control all the time. Earlier I implied that what you are going through would give a dedicated athlete pause to think. Every now and then it is alright to spoil yourself. What is happening to you is extremely unfair. But to survive, you can’t simply dwell on this unfairness – you need to make the most of what you have got. ***Be a survivor – don’t be a victim.***

For the moment, all that leaves are two more items, namely ***Chemo Brain*** and ***the importance of touch.***

***Chemo brain*** may sound like a cop-out or some lame excuse a person undergoing chemotherapy came up with to blame their erratic behaviour on. Be assured that it does exist and currently there is research being undertaken in the United States on this very subject. It is variously described like you are living in a fog or a diminishing in your mental aptitude. Don’t be alarmed, you are not losing your mind – in fact most people you will come in contact with will not even notice. You will be your own worst critic.

Just like your loss of overall body strength, you can take steps to reduce the impact on your life style. Again, just like the loss of body strength can be addressed in part by considered physical exercise<sup>2</sup>, possibly there are exercises you can undertake to at least reduce the impact of chemo brain. At present, this is only a theory but what have you got to lose. Start or continue to do crosswords and sudokus. Even try playing Solitaire on the computer – and win. But be warned that can be addictive and a great time

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<sup>2</sup> All physical exercise should be approached with caution after prior consultation with your myeloma team.

waster. Cross words can be another mind exerciser. Start simple but to test yourself, do them in biro. That can be a challenge. Seek out other activities that stretch your mind. Above all, be aware of the possibility that you might be affected and if it does happen, do not panic - you are not alone.

The other issue is ***the importance of touch***. Myeloma, as with most cancers, can affect you very personally and your sense of self-worth can take a real nose dive. As mentioned earlier, other people can react to you in a variety of ways. Remember, only a small part of communication is verbal. Other forms of communication include body language and touch. Touch can be extremely intimate, in the nicest sense of the word, and can convey messages of support and understanding beyond words.

Having someone squeeze your upper arm or simply lay their hand on your shoulder can often express more empathy and understanding than words. If you are lucky enough to have grand-children, then having one of them reach out to take your hand, or raise both arms and demand "Up!" can do more to restore your self-worth than any volume of words from a sympathetic adult.

Do not be afraid to reach out and touch your self – that is your self, not yourself. This is not the lyrics for a Chrissy Amphlett song. At times, people can be wary of breaking the ice themselves, possibly they are unsure of the reaction. Show them that you are still you, the myeloma is only a part of you.

It is easy to give advice but much harder to take it, even when the advice comes from someone who should know. That is your choice, but, as in the advice given by some furniture stain and oil makers.

*'Test in an inconspicuous area first...'*