WHAT HELPED ME REGARDING CANCER:

One person's experience of living with cancer and chemotherapy

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(You are welcome to pass this text on to others. It would have helped me if I had been able to read of another's experiences, and so this text is offered in the event that someone might find something in it that helps them in day-to-day living with cancer and chemotherapy or radiotherapy. These pages are written as notes rather than as a refined flowing text.)

I am aged 51, and ten months ago had surgery for removal of cancer of the small bowel, followed by 24 weekly sessions of chemotherapy. A complication lies in also having Chronic Fatigue Syndrome (M.E.) since its diagnosis in 1993 in the same hospital, close to where I live in the North West of England.

Each of us is unique, and each must find the way that is best for self to experience living with cancer and its consequences, especially chemotherapy and/or radiotherapy. What follows has been relevant for one individual, but I know that not everything will be appropriate for every other person. Individuals develop their own ways of coping.

I have known some people with cancer who have set out to be extremely busy, saying that that would take their mind off things. I have met some others who turned in on themselves to a great extent, tending to lead to depression and/or self-pity.

For myself I thought it essential to be fully aware of what I was going through, to live the dayto-day experience, to live it fully. The poet R S Thomas wrote: "We had the experience but missed the meaning" and, difficult as I knew things would be, I realised that the deep-rooted experience would be valuable for me as well as (possibly) having a knock-on effect that might be of some help to others. Bad as it is to have cancer, this is a profound human experience, shared by many. No matter how terrible and demanding the experience, I knew it would be a 'waste' if, through it and at the end of it, I had not learned something, not changed something about my life, not become a 'better' person, not opened myself more to others, not used it to attempt to bring some benefit to others.

I soon realised that my circumstances would lead to my having an effect on people, and I knew that it was up to me whether that would be a good effect or not so good.

With my background of knowing that it doesn't 'work' to fight the Chronic Fatigue Syndrome (M.E.) but to 'go with the flow', I set out with the same attitude regarding the cancer.

1 - What has helped me to remain positive?

The actor Paul Eddington (who played 'Gerry' in '*The Good Life*', and the Minister in 'Yes, *Minister*') was very ill with cancer. He remarked that people tended to say to him, "*You're brave*." He said that he always replied that there really was no alternative but to seek to be positive.

Those who look for what is positive in situations (and, indeed, in people) will find it. I had to ask myself: *"What am I going to do with this bad thing that has happened to me?"* The only response, really, was to say: *"I will seek to be positive, and I hope to be a better person for what I will go through."*

Surely it is one of life's greatest lessons to live fully in and through whatever the circumstances in which we find ourselves. We can bring good from bad things that happen to us. Over the years in reading about and meeting people who have suffered greatly, it has helped me to appreciate all the more that bad things do, indeed, happen to good people, and we need to ask ourselves how we can bring good out of what is not good, transforming one into the other.

The way we usually look at ourselves and accept ourselves most certainly has a bearing on how we respond to serious illness. For me the best thing was to be sure to set out to live at peace with myself.

Essentially, of course, it is the body that heals itself, and the purpose of medicines is to optimise that process. I knew I had to ask how I could promote the best conditions for the body's own healing processes to do their best.

a) WHAT IS LIFE-GIVING

<u>A human need to sense 'success'</u>

- Realise that being seriously ill is not a matter of *failure*. Society tries to isolate the sick from its focus, and some people seem to think (until they become ill themselves) that those who are sick are somehow 'deficient' in themselves.
- Acknowledge that sickness does not 'define' everything about you as a
 person. Know that you <u>can</u> still live fully as a human being whilst extremely ill.
- Seeking to do and experience things that are life-giving and life-promoting can counter a possible feeling of 'uselessness'. Any such negative sense can be transformed into a 'sharing in creativity'.
- A sense of 'success' (and of 'achievement') is needed each day. Every day, for example, I play some games of Solitaire on the computer: something simple, usually 'win-able', leading to a sense of 'success'.
- Use of not too difficult puzzles and quiz books can contribute to a sense of 'success' and of still being 'creative'.
- Don't dwell on what you <u>can't</u> do, but focus on and appreciate what you <u>can</u> do.
- After a while you could make a mental note of a 'wish-list' of some *realisable* things you would like to do whilst still amidst difficult circumstances.
- Do something that you can see change and develop, like growing flowers from small plants or seed.
- A time-consuming task may appear unachievable or, at the least, particularly

daunting. One big or time-consuming task, though, can be broken up into several smaller tasks, which are not only 'achievable' one by one, but can also be the means of experiencing a sense of 'success' not just once (as in a single large task) but for each stage of the more numerous smaller tasks. Breaking things up in this way, then, can lead to a greater overall sense of success, of achievement, in your circumstances. For example, instead of aiming to wash, dry and iron clothes as a single overall task, it can be a help to consider those three elements as distinct tasks, with each of them leading to a sense of success, of achievement. Breaking things up into smaller achievable units can be a way of giving self more 'ticks' for completed tasks, with each 'step' contributing to feelings of success and achievement. This process can help, too, in self-confidence.

<u>Stimulating the senses</u>

- Have flowers and flowering plants around: they are life-giving. When in season, have some bulbs growing slowly in the house (such as hyacinths and daffodils). Flowers and plants (especially when in bloom) can promote good feelings.
- I recall a beautiful day and a visit to a well-stocked and well laid out garden centre: it raised my spirits a lot. Unfortunately, though, it left me feeling very drained for several days but I was glad to have done what I did.
- Good smells can be life-promoting, such as from scented flowers, good aerosol sprays, aromatherapy oils which can be poured into a bath or into a bowl of water in a room.
- At least three times a day (and preferably in a garden) have a walk outside, however gently and briefly.
- Appreciate the smell of the air during or after rain.
- Fresh air can leave you feeling good, and it can be helpful to sit outside (in the shade, if necessary, and whilst warm enough). Inside it can often be beneficial to have windows open to let fresh air in and allow it to circulate and, possibly in conjunction with that, it can be of help to have an electric fan blowing cool air on to your face.
- With a likely increase in the amount of time spent in bed, it is good to change bedding more frequently so as to sense the comfort of freshly-laundered sheets more often than usual.

<u>Attitude and keeping perspective</u>

- Whilst outside, look at plants and trees, but also look above at the sky. Many of us tend to look at little above eye-level. Instead of tending to keep the eyes fixed downwards, looking outward and upward can help remind self to widen 'inner vision' and grow in perception.
- Be sure to go out occasionally, even simply for a drive in a car.
- Being by water a river, lake or the sea can be therapeutic.
- On going to a high place a person can look downwards and view how small everything appears below: people, buildings, roads etc. Looking down from a high place can help in keeping a sense of perspective and balance.
- Watch life-giving programmes on TV e.g. some nature or garden programmes, as well as those that portray the positive human spirit.
- Watching travel/holiday programmes can allow your mind to 'go on holiday', even if your body can't.

- The likes of illustrated travel/guide books (such as the excellent *Dorling Kindersley 'Eyewitness Travel Guides'*) can be glanced at or read not so as to think *'if only'* but, instead, as a means of having an afternoon 'visit' to York, Venice, Paris, Florence, Edinburgh.... Such things can help in keeping horizons wide.
- It's essential, of course, to rest. Don't be put off by the thought that there might exist even one person who might think you are being lazy because you rest a lot!
- There will be times when you can set out to enjoy yourself and not only enjoy yourself but <u>enjoy</u> enjoying yourself (even when simply resting).
- Watch or record some good comedy programmes. Being tuned to comedy helps retain a sense of balance and perspective, as well as an encouragement not to take self too seriously. Having some such programmes recorded will enable you to avail of them when special need arises.
- It is essential to laugh and to smile. It can even help to stand in front of a mirror and begin by 'forcing' a smile upon your face. Smiling and being cheerful certainly helps. Smiling also serves as a reminder that we still have choices, and can choose to be happy or sad. It is our frame of mind do we consider a glass to be 'half-full' or 'half-empty? (and not what happens to us) that dictates whether we are generally happy or sad. In being cheerful and smiling we can also be life-giving and life-promoting to others and there is a tendency in society to think that sick people cannot be happy and positive and life-giving to others.
- It is important at times to realise that you need to 'lighten up', not to be 'intense'. Even slowly moving your shoulders up and down and around can help in that, as can taking several deep breaths.
- It is essential to be able to smile and laugh at self.
- A bath or shower can help raise spirits.
- It's easy to let little things get out of proportion, since you can be all-consumed with what is happening to you. Be ready to 'bite your lip' to avoid overreacting to someone or to something that has happened.
- In whatever your circumstances, set out to look for the best e.g. I told myself that it was good to have the chemotherapy administered by injection in the back of the hand because, taking a short time, it meant I could go home quickly. But if, instead, I was to have had the slower injection by drip, I would have been determined to find something positive to say about that e.g. it would give me chance to sit quietly and force myself to go into deep relaxation in a chair, or that it would give me the opportunity to chat occasionally with someone else going through similar difficulties, or that it would give me chance to sit and read a light book, etc. It is important, then, to have the attitude of taking whatever your circumstances are and looking for (and convincing yourself regarding) positive things about them. Again, it is a matter of individuals choosing how they want to approach life.
- I thought that I should be aware that many in my own town, country and world would be going through similar things as me. I knew that it would be right to set out to 'identify' with others, and that would also extend my horizons and limit any tendency to self-pity.
- You will need to consider a different time-scale now, compared with how you probably looked at things in the past. No longer is it a matter of thinking a month ahead to a planned holiday; now it's very much a day or a few hours at a time and, at the other end of the scale, the length of your course of chemotherapy may be six or seven months.
- Pause and reflect about how individuals really do love and care for you.
- Remind yourself every day of many good things, of blessings, in your life.

<u>Communicating with and meeting others</u>

- I decided I would be completely upfront about the cancer, and so kept family and close friends fully informed. Whenever others asked, I would respond with detailed information when appropriate. As well as wanting to be 'open' (such being my character) I thought that it might help some of those who really care for me and love me, and might help older people in particular, for whom the thought of cancer tended to be frightening. I am told that my talking openly has been of help to some people who were afraid of having serious illness themselves, and to some of an age for whom 'cancer' generally implied death in the minds of many, which is no longer the case, of course.
- Some people have avoided saying anything whatsoever to me regarding health, perhaps because they might have felt that cancer is 'contagious' in mentality, or because they cannot deal with being uncomfortable, or because they don't know how to begin to say anything. It can even be that someone will cross the road to avoid the person who is very ill, despite knowing them well. It is important to be generous in not being judgemental. Remember too that, in profound illness, sick people can readily get things out of balance, out of perspective, and so can those around them.
- You may have occasions of meeting individuals who will surprise you in different ways. You may find that some whom you did not relate with particularly well now touch you in various ways with compassion and generosity.
- Maintaining conversation for a long time when particularly ill can be very demanding. Sometimes it is the case, though, that visitors to hospital (or to your home) have difficulty in maintaining conversation, leaving it to the patient to take most of the initiatives!
- When matters got particularly rough, I have had occasion to make a mental note in advance of 'topics' to talk about before visitors arrived. And this ensured that the conversation was less likely to remain limited to illness!
- Limit your contact with people if you are having chemotherapy, because your immune system will be diminished. Let no one near you who has a cough or a cold. Hopefully you can avoid entering a doctor's surgery where, close to people who are ill, you could so readily contract others' infections. It is the same if considering going to see a loved one in a care home or in hospital. It would be very risky.
- If you are resident in hospital, discourage strongly anyone visiting you who also happens to be having chemotherapy: they would be at risk because their diminished immune systems shouldn't be subjected to infections they may encounter.
- For your protection, people visiting you in hospital should be certain to use the antiseptic gels provided before they make contact with you (and, for their protection, should apply the gel on leaving).
- Receiving a lot of cards, letters and emails, I have had occasion to type a short letter occasionally and photocopy it to various people or send a common email, rather than use up limited energy in replying personally to many.

I have very much appreciated and have benefited greatly from support and encouragement, love and care and kindness - shown in many ways from near and far, by people around me, by others visiting, phoning, emailing, sending letters and cards, passing good wishes on via others, and praying for me. All of that has been a great blessing and much appreciated. During the course of the chemotherapy (and the preceding months of pain and disorientation) I grew to appreciate very much each and every act of kindness. It can be very touching on appreciating that others <u>want</u> to 'accompany' you, 'be with' you, 'identify' with you, be compassionate and suffer alongside you.

b) ACCEPTING THE REALITY

- Some people have said: "You're looking well" when it was abundantly clear that I was not looking at all well! Comments like that could have the potential to discourage. but I realised that those people wanted to voice something that they thought would be supportive, but they just didn't know what to say. Personally I found it very supportive when people expressed the reality of things e.g. "You don't look at all well", or "You had a rough day vesterday" - since, in my eyes, that implied that the other person was realistic and honest and, especially, was willing to see me and accept me for who and how I was, rather than seeming to pretend otherwise. Some of the occasions when I have been most touched, in fact, have been when people have reflected the reality of the situation e.g. a nurse, on my visiting the hospital in the early stages, said: "You don't look at all well." That comment actually served as a great boost to me, being an acknowledgement of how things really were: people recognised the reality of how I really was and 'confirmed' that to me. From that comment I picked up that that nurse was perceptive enough and concerned enough about me to speak frankly and honestly with me. She didn't 'pretend' that things were other than they were. She didn't do as some tend to do, pretending that everything is much the same as in the past when, evidently, it isn't!
- Grow accustomed to looking in the mirror at how you may have changed in your looks
 - but accept that, rather than avoid it or deny it. Don't be negative about it. There is no
 point in complaining about it or saying *"If only it was different..."*. If you grow more
 content with seeing yourself as you really are at the moment, you will grow more
 comfortable and at inner peace with yourself, and will be more likely to relate
 constructively with others.
- There is the old joke of the country farmhand being asked by a motorist how to get to a certain place, only to be told, *"If I were you, I wouldn't start from here!"* The reality for us, of course, is that this is, indeed, where we are. It is from <u>here</u> (and not from somewhere else that we would prefer to be) that we have to proceed.
- Perhaps it's a bit like with Alcoholics Anonymous who say that the first thing is for the person to acknowledge that there is a problem. We do have to acknowledge that we have cancer not pretend that it is other than what it is. I can say: *"I have got cancer. It is a terrible thing to have, but this is where I am starting from, and I am going on from here. I will be positive and constructive, and will seek to 'transform' the negative into something positive. I'll seek to be a better person through all that happens to me."*
- Yes, it's bad news to have cancer, but I also considered it 'good news' to be told, at long last, <u>what</u> it was that was seriously wrong with me. Knowing that it was cancer meant that I knew more than I did previously about my situation, and ways to move forward became possible.
- It's quite natural and understandable to be worried but, as time goes on, ask yourself how worrying can possibly be of help to you!
- Writing can be therapeutic, allowing a person to reflect and sort out some thoughts and feelings.
- Some people write an occasional entry into a diary or on computer. For some people this is in the form of writing to themselves, as if to say, and then they might 'reply' in a letter back, writing as the best friend hopefully that they are to themselves.

c) <u>SELF-PITY AND ANGER</u>

- Terry Waite, held captive in Lebanon for five years, tells of three resolutions he made when first captured: "No regrets, no sentimentality, and no self-pity.... Self-pity kills. It absolutely destroys."
- Don't go down the road of "Why me?"
- You may have occasion to feel that a doctor or health worker or 'the system' possibly may have let you down. Don't waste your limited energy on bitterness or having regrets or feeling bad towards people or situations that would be a 'cancer' of its own. Don't fuel any anger or similar feelings: it would eat away at you and would not correspond with an attitude of generosity and 'letting go' on your part.
- There is no point in saying, *"If only...."*. Accept the reality of how you now are let things go, and move on.... Living in the tension of regrets can only diminish the efficacy of your body's own healing mechanisms. It is essential to *'let go'* of anger, regrets, frustration and anything else that is negative: it is most important to <u>move on</u>.

d) OTHER FEELINGS

- It is important to express what you are feeling.
- There can be a sense of loss with an accompanying need for some kind of 'grieving' for what no longer is, but then.... move on!
- Think in a positive way that there are many others in a similar situation to yourself, and think of those who have no support from others. In hospital you will encounter some of them and their relatives. You need to bear in mind that some people when in difficulty or very low, sometimes tend to avoid eye contact.
- It is hardly surprising that people feel terrible at times in body, mind and spirit but I
 knew that, accepting the reality of how things were for me, I would rather have those
 deep but difficult and draining feelings, than be a cold, insensitive person who
 wouldn't be touched as profoundly by the deeper emotions and feelings of this very
 human experience.
- During these times, physically touching another and being touched is even more important than usual , and conveys much.
- There are times when it is good to cry. I recorded the Australian soap, *Home and Away*, during the time of Kane's testicular cancer, and I replayed certain narratives which touched me. I found it emotional to watch a TV documentary on two men with cancer of the oesophagus.
- There will be times when the playing of certain pieces of music may help you get in touch with and express certain feelings as will some films or excerpts from films.
- Whilst you will want and need at times to be with someone else or with several people, but there will be other times when you simply need to be alone. This is a unique experience and even those who love you greatly and who walk beside you, still cannot feel exactly what you feel in your body, mind and spirit. Be convinced that there is a real need to have times of being alone (but, hopefully, not of loneliness): times when there is no noise or other distractions around you times when you become more 'present' to yourself, more aware, and probably 'at peace' with yourself (however difficult things might be at the same time).
- My determination to remain positive didn't stop me considering various implications that would arise if, indeed, I was to get worse with the cancer. That's being realistic.

2 - About chemotherapy

Some people have surgery and no chemotherapy. Some can't have surgery but have chemo that can shrink the cancerous growth and so reduce problems. Some have chemo before surgery. Others have surgery to remove the cancer and then have chemo which is precautionary: to 'mop up' any cells that might have escaped and migrated which, without the chemo, might develop as secondaries elsewhere.

It is very important to have someone accompany you to chemotherapy (and to appointments with specialists, etc): not just for the convenience of someone driving you there and back, but because others do want to 'accompany' you in a deeper sense, and that can be mutually enriching. Having someone with you also allows you to hold a conversation, take your mind off something, and 'lighten up' in thought. Someone's accompaniment is much appreciated on many levels.

Days before the chemotherapy course starts you will have a talk with your oncologist (cancer specialist). On the first day of chemo it was part of the programme to have a lengthy chat with a nurse qualified in these areas. That, too, was very helpful. The hospital insisted on my realising that I could phone them at any time in the coming months to have a chat about things, and I found it very helpful on the couple of occasions I did phone, such as to mention concern over certain symptoms. When feeling particularly unwell, it was possible to postpone the chemotherapy by a week, but I was told that it was not advisable to delay chemo by more than a week at a time.

The effects of chemo can be less demanding for one person than for another, and it also depends on what kind of cancer the individual has, and what kind of chemo is prescribed as the most suitable.

Depending on the type of chemotherapy that you need, it might be given by injection in the back of the hand, or intravenously by a drip (which takes time).

At the first chemo session I was given packs of medication regarding diarrhoea and also constipation, lest either (or both) of those symptoms should affect me in the future, and those medications were kept topped up as the course progressed.

A supply of anti-nausea pills was also given to me each week. As the course progressed I was tried on different anti-nausea pills, across a range available, so as to find those that worked best for me.

As cancer is fast-growing cells, chemotherapy is toxic chemicals that are designed to kill those fast-growing cells. Unfortunately chemo can also affect other fast-growing cells of the body, such as (but not always all of these):

- the scalp (leading, in some, to hair loss). I was fortunate not to lose my hair; it depends on the kind of chemotherapy. Losing hair tends to impact more on females than on males, who generally aren't very concerned about it, since baldness is a common sight in men of all ages (and is even trendy with some!).
- **the lining of the mouth** (leading, in some, to mouth ulcers, which in some can be deterred by the use of salt-and-water mouthwashes after eating);
- the lining of the intestines (leading, in some, to diarrhoea and/or constipation). At the chemists I bought packets of citrus-flavoured DIORALYTE for mixing with water and drinking after diarrhoea, as it helps replace body salts electrolytes which are important for health.
- the palms of the hands and soles of the feet (leading to dryness of those

areas, for which I was prescribed DIPROBASE emollient cream). Those areas also became very shiny (a very minor point). The tips of my fingers and toes became quite sensitive at times, even for blocks of several days at a time, and even weeks after finishing chemotherapy. On some occasions of washing my hands, or on having a shower (even weeks after the course of chemotherapy came to an end) the skin of my hands felt 'sticky' as skin touched skin with water between them.

I had a watering of the eyes due to chemo, and usually looked pale and drawn.

Fatigue can be very significant. There have been a few occasions when it has taken me a long time (and has been very demanding) in setting out to get up from my chair, undress, wash and get into bed - but the degree of fatigue was affected by the other serious illness I have.

Towards the end of the course of chemotherapy I knew I was to have a blood test. It was geared to detecting if there was a diminished presence of antibodies regarding cancer. If so, that would indicate that the cancer had not spread. At about the same time I had a CT scan which would have shown up any <u>non</u>-cancerous growths, if they had existed.

I was told that it would take about six months for the toxic chemicals to leave my body after the completion of the course of chemotherapy.

NAUSEA FROM CHEMOTHERAPY, AND NEEDING TO EAT

Prior to chemotherapy (prior, that is, to the previous surgery to remove the cancer) I had bad vomiting, diarrhoea, and difficulty in eating. Thankfully the vomiting ceased after the operation (which was to remove the cancer of the small bowel and a small section of the bowel in which it was growing) but chemotherapy gave me problems of diarrhoea (sometimes acutely so) and of bad nausea that was persistent.

- Being very conscious of diarrhoea, it was not wise during those times to take fruit (especially raw fruit), which otherwise would promote bowel movement.
- To help combat the nausea I have found ginger to be good: drinking nonalcoholic ginger beer (cold cans of '*DG Old Jamaica Ginger Beer*' I found to be the best), and occasionally gently chewing crystallised ginger (packets are available from some health food shops and some supermarkets). After a period of time, though, the eating of the ginger evidently formed an association in my mind with nausea and so, on eating ginger, I began to feel nauseous! It was 'anticipatory nausea'. I moved on to mint imperials, which were helpful but they, too, eventually began to suggest nausea. I finally moved on to Everton mints - and have eaten many to good effect regarding the nausea!
 - Using a particular brand of new soap triggered nausea: I discovered that its smell was the same as that of the gauze put on the back of my hand after chemotherapy.
 - I was told of a former chemotherapy patient who happened to meet her off-duty nurse in a supermarket. The former patient, although she had finished chemo some time before, vomited on simply seeing the nurse in the supermarket.
- A smell of garlic happens to be one of the things that triggered nausea for me during and for some time after chemotherapy.
- On waking up in the night nausea could hit me straight away, but it depends on individuals.

- Sweet things are more attractive to eat than savoury things. The chemotherapy unit often had chocolates in the waiting area, as something sweet can be of help with the nausea (but chocolate can lead to the 'runs').
- I didn't enjoy any meat.
- There were times when I asked for some particular food, but when it was ready I couldn't face it at all.
- It was very difficult for me to find any food that I was completely comfortable with. It often came down to toast (made of 'traditional' bread rather than steam-baked sliced bread). Putting orange marmalade on the toast, though, often promoted diarrhoea.
- I had a kind of metallic taste in my mouth sometimes: mints would help.
- I used to enjoy milk, but it began to taste 'off' and leave me with a bad aftertaste, as did many items of food or drink, and so I would generally follow anything with a mint.
- Powdered SLIPPERY ELM (powder mixed with milk and then heated as a drink with nutmeg for flavouring, and a little sugar) helped put a 'lining' on my stomach. Packets are obtainable from Health Food shops.
- I was prescribed high-calory drinks manufactured by various companies. The best in far by taste that I have had has been '*FRESUBIN energy drink*', offering many flavours. Not all products nor flavours could I manage. Milk or yoghurt-based drinks I thought I would like but, having a problem with milk, I didn't find them palatable. It will depend on the individual.
- Non-pasteurised foods such as 'live' yoghurts and paté should be avoided, I was told.
- Generally, I found it much better taking liquids rather than solids (e.g. good quality soups such as liquidised home-made soups, accompanied by a little good quality bread).
- Food and drink containing lemon appealed to me, perhaps because of the tang and refreshing nature of lemon e.g. fish with lemon, lemon drinks, lemon meringue pie (and lemon sherbet sweets).

3 - Other daily problems and occurrences

- Sleep can be very difficult and very frustrating at times, but I know I shouldn't sleep longer than planned in the mornings as that would affect my body clock. The latest I've managed to get to sleep is after 5.00am, and it's not even always the case that a good sleep will follow the night after! Very often I felt considerably 'over-tired'.
- The self-discipline of getting up at the same time each day (even though feeling dreadful and possibly having had little sleep) can help remind you that you still have control and choices in your life, instead of allowing circumstances to dictate everything you do. It is also important to retain 'anchor points' of 'routines' of times of getting up and eating, etc (and an established practice of the likes of the Red Cross when dealing with natural disasters and other crises, is to help people have the 'stability' of certain routines).
- I have often found it quite difficult to concentrate sometimes in following a conversation (which can be very draining) or in reading. When unable to read a book, reading short articles (such as in *Readers' Digest* or in other magazines) can be of help in continuing the stimulation of the mind, extending horizons.
- Needless to say, stay well away from cigarette smoke.
- You may be surprised as to how often you find that cancer is mentioned in films, dramas, soaps, the news! Perhaps it's like buying a car of a certain colour and then seeing for the first time that there are far more than a few cars of that same colour on

the roads!

- After the initial surgery a District Nurse came to see me to remove the stitches. She then asked if their service could be of help by calling in to see me at agreed intervals. That was very encouraging as it gave me someone 'outside' my usual sphere with whom I could chat and, of course, they had medical knowledge and expertise. They also had experience of other patients with cancer that could be of help. We agreed that a District Nurse would kindly come to see me (and make notes) about every three weeks. A date would be agreed upon at the end of each session.
- For some time I have been receiving multivitamins on prescription called FORCEVAL.
- It is a myth that all people with cancer are thin!

4 - For others to consider

- It is essential not only that messages are passed on but that the one who is ill be told: "so-and-so was asking after you". It is very encouraging. This, of many points I could put to people, is very, very significant. I much regretted it when people seemed not to bother to pass on such messages, and I often felt hurt on discovering that that had occurred.
- If, in the presence of the sick person, someone does little other than cry or regret the circumstances, it really is not of help. It can even lead the sick person to wonder if the other individual is more concerned about the impact on himself/herself than on the one who is very ill.
- If an enquirer has the attitude of being about to look at his/her watch after asking the sick person how he/she is (and even before waiting for a response), they shouldn't bother asking in the first place!! Such an attitude conveys much! Some enquirers convey by their body language that their question has only been a formality!
- It is most off-putting and thoughtless if, on the telephone, a caller asks the sick person how he/she is and then cuts off the sick person's response in no time. It is insensitive and offensive, especially if it becomes evident that the purpose of the call is to ask and expect the sick person to do something for the caller.
- It does annoy me if I hear anyone complain of having the likes of a sore throat, especially if they are insensitive enough to say such things in my presence, or to look miserable because they have a headache.
- It could be useful for others to know that it is not usually helpful to be asked 'closed' questions (i.e. those calling for a 'Yes/No' response) such as "Did you have a good night?" The phrasing of closed questions <u>can</u> imply that the questioner is being polite in asking a question and isn't looking for anything but the briefest of responses. That particular question could also imply that the sick person 'ought' to have had a good night! Closed questions <u>can</u> lead to a sense of negativity. Instead the question could be phrased: "How was your night?" Such a question leaves the sick person with the option of giving a brief response or a longer expression of deeper feelings as to what is happening. It is good if others not only ask "How are you?" but give opening questions like "How's the morning been for you?"; "How have you found the treatment this week?"; "How are you finding food these days?"
- Bear in mind that lengthy conversations (even on the phone) can thoroughly tire out someone with cancer and undergoing chemotherapy. The expending of mental energy is equivalent to the tiredness that physical work brings about.
- In letters or cards sent to the person who is ill, sometimes adding such a phrase as: *"No need to get back to me"* can reduce small pressures in someone who would normally respond promptly.
- It can be helpful occasionally for someone to give advance notice that they are going out somewhere, asking if the sick person might like to join them.

It has touched me when people have said words like: "It must be tough-going"; "I admire the way you're coping"; "I wouldn't have managed with things as you have done"; "It must be so difficult and take so much out of you"; "I can see that you're always positive"; "It must be very frustrating"; "It must be difficult being cheerful when you're so ill." I remember being very touched, too, when someone said: "I'll be praying for you at about midday each day." (Another could have said, "thinking about you...").

You will grow to appreciate many people a great deal, and also the special moments that you will experience, as well as the hours and days when you are feeling better than at other times.

IN GRATITUDE

I am very grateful to be one of those whose lived experience of God's presence and of faith and of sharing with other Christians, remains a very great blessing and the core of my life. My experience is not of God 'giving' me illness but of Jesus (God-become-a-human-being) choosing to accompany me and suffer alongside and promise fullness of life. For many years I have found that praying influences my attitude and so can help in 'transforming' difficulties, and even in deriving benefits from them. I have a list of particular people I pray for (and offer the difficulties and suffering for), 'allocating' individuals and intentions to specific days of the week. This 'transforming' is a way of going beyond the utter depths to which such illnesses can bring a person, and can contribute to the 'making sense' of the bad things that are happening to the individual.

> If anyone is reading this on printed sheets of paper but would like a free electronic copy of the text, it can be emailed to you. Someone will respond to you if you request that that attachment (93KB) be sent to you:

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SIX BOOKS by Nicholas Hutchinson

To look at the author's six books, go to the publisher's website at www.matthew-james.co.uk Click on '*Catalogue*' Against '*keyword*' type in the word '*praying*'. There, amongst others, the author's six books can be viewed: 'Lord, Teach us to Pray', '*Praying Each Day of the Year' –* 3 volumes, '*Walk In My Presence' –* 2 volumes.

A BOOK ABOUT LIVING WITH TERMINAL ILLNESS AND ACCOMPANYING LOVED ONES WHO ARE DYING

In late 2008 or early 2009 Dominican Publications in Ireland will be printing a resource book to which Brother Nicholas Hutchinson and others will have contributed. The book explores living with terminal illness and accompanying loved ones who are dying. Queries can be made at www.dominicanpublications.com

This text was found at the homepage of www.prayingeachday.org