

Nasopharyngeal Carcinoma (NPC) Patient Information

This webpage was started by a NPC patient in Hong Kong. The main objective of this webpage is to provide comforts and confidence to fellow NPC patients and other cancer patients and their families; by reading the experiences of those who have gone through radiotherapy and chemotherapy. This site also

1. provides a Comments Page for NPC and other cancer patients and their families to send their observations, please send them to (tkto54@hotmail.com);
2. promotes the awareness of NPC to the general public.

My experience was based on the concurrent chemo- and radiotherapy treatment I received for NPC at 1997 in Prince of Wales Hospital (PWH) in Hong Kong, the treatment for NPC might be different in other parts of the world (e.g. Guangdong, Fujian, Taiwan, Singapore or Malaysia). However many of my observations might provide you with some insights. If you are a fellow patient from other parts of the world, your comments are most welcome; please send them to me (tkto54@hotmail.com) and I will post them on the Comments Page.

It is **not** the objective of the Comments Page to seek and to provide medical opinions. Patients should consult their doctors and other medical professionals. It is not a place to leave complaints and allegations, they should be directed to official government channels. I am putting some of my observations on the concurrent chemo- and radiotherapy treatment together with advices / experiences of other authors on this site. I sincerely hope that our experiences could provide some comforts to NPC and other cancer patients and their families in their time of need.

Useful Links:

1. Hong Kong Cancer Fund provides an informative background for all cancers common in Hong Kong including NPC:

<http://www.cancer-fund.org/eg/index.html> (English)

<http://www.cancer-fund.org/cn/index.html> (Chinese)

They provide information and advices to cancer patients and their family.

2. Hong Kong Anti-cancer Society has an excellent page on the symptoms, treatments of NPC patients, supports offered and advices to cancer patients and their family in Hong Kong:

<http://www.hkacs.org.hk/> (Chinese)

You are most welcome to print and to quote any of the contents, however it is the normal practice to acknowledge the authors if you are quoting their words from the contents or from the Comments. Please direct useful links and comments to K T Ko at ktko54@hotmail.com, they will be posted in this site.

Last updated: 20th August 2002

Face the Challenge! (and there is no answer to ‘Why Me?’)

Nasopharyngeal Carcinoma (NPC), I did not know what it meant, let alone spelling or pronouncing it. I was told that I was suspected to have NPC after an examination of an enlarged lymph node on my left neck. NPC is a malignant tumor spread from an area behind the nose via the blood stream, it is most common in Southern China and almost exclusively affects Cantonese; amongst the top three occurring cancers in Hong Kong for many years. I was confirmed to have NPC by blood test for the Epstein-Barr (EB) virus and Magnetic Resonance Imaging (MRI) in the hospital. The dice was set as the biopsy (taking some tissue from my nostril for detection of cancerous growth) result finally confirmed the suspicion.

The first reaction of my wife and myself were shocks and disbelief. I was at the peak of my physical well-beings. At 42, I worked out in the gym 3-time a week and did a 30-minute run 3-times a week, I had never felt fitter all my life. I had a happy family with my wife and our 12 year-old son, and I loved my academic job in the University. My work kept me very busy and occasionally stressed. The cancer got me while I was at my prime.

The question of **‘Why Me?’** raised many times in my mind, I am certain that all patients will ask the same question when facing the momentous threat of their life. I learned after many sleepless nights that there is no answer to such a rhetorical question. I might as well ask ‘Why am I here?’ or ‘Where are we heading in our life?’ Having a cancer in your body is like a reverse lottery and I was randomly selected for such a ‘gift’. Being selected, I had only two choices: ‘passively wait for my turn or positively face the treatment and see what I am given.’

For my part, I was really enjoying life and determine to give the best fight of my life for my life. My wife told me, “to survive this crisis is the biggest achievement of your life”. She promised to give all her support during my treatment (and she has never missed a session accompanying me to treatment or consultations). I told myself that I must stay in good physical and mental shape. My son was very optimistic, like any 12-year-old, he believed that there is nothing on earth that his father could not handle.

For a man who had very little previous contact with medicine, the uncertainties of the treatment depressed me a lot. The pain and their side effects seem daunting initially. My

first reaction was to draft my will and discuss options with my wife upon my departure in the most tactful way possible.

However I stayed positive throughout my treatment, I wrote the following in my diary just before the treatment:

‘As far as we known, NPC has a strong genetic predisposition with certain environment factors for its cause. My Chinese ancestry provides me with the splendors and grandeur of an ancient civilization; it also makes the possible fatal connection. This is ironic for a multicultural man (a Hong Kong born Chinese brought-up in Australia) that my roots finally caught up with me. It would catch up with me irrespective of where I lived. It provided the ultimate end to my identity crisis.’

‘As for me, after I have learned more about the NPC treatment and its schedule, I have come to accept this illness as my destiny. It is God's wish and I have no alternative but to accept my fate, do my best and to accept its outcomes. I know that the treatment can at least extend my life, and I also know that NPC can be healed with treatment and luck (i.e. I will die of something else). One other way to look at life is to see its greatness. I have a beautiful life, filled with tears and joys, fulfilled aspirations and minor achievements. Whatever the outcome of my fate, I will accept it with thanks, with pride, and definitely with no regrets. Any extension of my life could be seen as a bonus, which should be earned. Whichever way I am looking at it, I know that life at this stage should only be positive and cheerful if I want it to have a purpose and to stay sane.’

KT KO, Last updated: 1st September 2001

How Difficult is the Treatment (from the patients' point-of-view)?

To be honest, I was apprehensive about the treatment. The pain and their side effects seem daunting to me at first. The treatment for Nasopharyngeal Carcinoma (NPC) consists of radiotherapy and possibly concurrent chemotherapy. Radiotherapy is targeting the cancerous growth with high-energy micro rays. As NPC is extremely sensitive to radiotherapy, it is the primarily treatment for all stages of NPC. For lower stage of NPC, radiotherapy is a curative attempt. In Hong Kong the radiotherapy takes approximate 33 sessions and depending on the stage and response from the treatment, additional sessions might be applied. Recently internal radiotherapy from a radioactive implant and concurrent chemo- and radiotherapy (CRT) are also very popular for NPC treatment.

I have had CRT as my treatment experience. The chemotherapy consists of weekly dosage of intravenous injections of a cytotoxic drug (in my case, cisplatin) which destroyed the cancer cells. As it is introduced into the blood stream, it reaches and hopefully destroys cancer cells all over the body. The injections were made in the same period as the radiotherapy sessions. The number of dosages you have will depend on

your response to the drug. Blood tests will be taken prior to the long intravenous injection in order to ascertain the conditions of your health.

The treatment consists of many injections, endoscopies (putting an optical tube into your nostril for observation), blood tests and biopsies (taking some tissues for pathological testing). Yes, the treatment will be painful at times, but not unbearable because of the anesthesia. You will get sick if you are on chemotherapy, because the drugs used are toxic. It will be uncomfortable at times, but remember they are using all available means to combat a very dangerous cancerous growth in your body.

I remembered what my friend Kevin said to me prior to my treatment "Look at the big picture, this uncomfortable period is only a small portion of your life." To think back, it was not the pain I remember. It was the dedications and the kindness of the people who treated me (in PWH of Shatin, Hong Kong) I remember. It was the tears from my friends Bill and Man when they learned about my fate I remember. It was the volume of get-well cards from friends I remember. It was the countless chicken soups from Man I remember. It was the courage of my wife (who carried me through my most difficult time) and the confidence of my 12-year-old son (who gave me a good reason to continue) I remember.

K T KO, Last updated: 7th September 2001

What you should do right now?

If you are diagnosed to have NPC, prepare yourself mentally and physically for the treatment! Mentally, prepare yourself that your life will change forever by the NCP and its treatments. Accept them as part of your fate with grace and dignity. Your adaptability will allow a good quality of life despite of the changes. Stay optimistic because there is no other way you should look at life now. Let your friends and colleagues know about your fate and show your determination of returning to a full routine upon the end of treatment.

Physically, remains fit and strong; if you take part in regular exercises, keep to the regime and listen to your body for signs of tiredness. If you have not been exercise, it might be a good idea to take some time off with your companion for a leisurely daily walk. If conditions allow, take some sick leave from your work. You need the time off to rest and to relax. However it is not unheard of, patients continuing their work while attending early or late sessions of radiotherapy in the hospital. Eat sensibly, maintain a balanced diet of vegetables, fruit, rice, meat and fish. You will prefer a more liquid diet as your mouth gets dry. You might also find food tasteless as you lose the taste buds. Tell yourself that you are eating for the nutrition to fight a large battle inside your body. If you are feeling tired, take as much rest as possible.

You should also get to the treatment as soon as feasible. There is normally a long queue for radiotherapy machines in major hospitals. Take the earliest available date, there is no point in waiting because nobody can predict the rate of growth of your cancer. In Hong Kong, all the major public hospitals have their oncology team specialising in the treatment of NPC. They are some of the most experienced teams in the world.

Lastly, you should also make some arrangements on the possibility of your departure. A will should be drafted in order to avoid any delay and inconveniences. Financial details should be documented and updated: house deeds, bank accounts, investment accounts, superannuation benefits. Although one wishes that these arrangements are unnecessary, the benefits of leaving a tidy financial arrangement to your family will make the job worthwhile. Be aware of the sensitivities of your partner / companions, they are normally as shocked as (if not more than) you are. Talk to them, one should hope that talking about it would relieve some of the associate anguishes and stresses.

K T KO, Last updated: 5th September 2001

What are the Side Effects of the Treatment?

The traumatic treatment has had its side effects over the short and long terms. For the short term, a dry mouth caused by the damage to the saliva glands, loss of hair because of the chemotherapy as well as the radiotherapy (in both cases, the hair will grow back very quickly when the treatment stops), loss of taste as all food tastes dull (due to damages to the taste buds), loss of appetite, feeling fatigue (your body is fighting a big battle), vomiting due to chemotherapy (this could be reduced by taking an anti-sickness drug known as antiemetics), and a pins-and-needles feeling in the finger tips are the side effects of the treatment. It should be noted that most of the above symptoms disappear within 12 months after the treatment is stopped. Your doctor will advise that you should exercise your mouth daily by opening it wide. This is necessary in order to avoid fibrosis (inability to open the jaws or to speak) caused by the stifling of your mouth after the treatment. You should exercise your mouth daily despite some of the discomforts caused by infections.

More about your appearance during the treatment, three items stand out. Your hair loss might form a big "M" sign at the back of your head in the latter part of your treatment. It is caused by the position of high energy beam entering and leaving your head. The hair follicles are damaged by the radiation and loss. If you feel a bit embarrassed by it (which you should not), a hat and a cap will do the job in hiding the baldness. Your skin will also be damaged by the high energy beam and become much darker in your face and neck. Don't touch it, don't wash it (don't wet it when you shower or bath) as it might cause more damage and possible infection. When the radiation stops, old damaged skin will peel off and layer of new lighter skin will appear. Finally, your weight could be reduced because you will lose your appetite and you will find it difficult to swallow due to sore

throat and mouth. Protein and vitamin supplementary drinks ("Ensure" is one of the product readily available in the shop) could help you through the most difficult time. Remember eating well will allow quick recovery. You might like to buy some of the supplements soon and try it first as they taste "different" and might take some time to get accustomed to. If you don't like them at all, try some large bottled baby food. I am told that they taste good.

In the long term, some of the above symptoms will still persist. The most likely one is the dry mouth caused by the reduced amount of saliva and the darkened skin caused by radiation. The dry mouth will change your preferences on food, moist food are often preferred. However you could still enjoy dry food when it is accompanied with drinks. With other symptoms, you should see your doctor as soon as possible.

K T KO, Last updated: 7th September 2001

Can Faith Help?

Religious belief is very often required to take us through our most difficult times. It gives us the strength to endure, it gives us the reasons to live. If you have a faith, I am certain that you could rely on it for this difficult period. I believe in God, but do not have an established religion. I respect all faiths in all cultures. However my wife is a devoted Catholic and she prayed very hard for my well being and I am thankful to God for my second life. If you think that you could obtain more support and comfort from established religions. This might be the best time for you to become a faithful in your own faith.

K T KO, Last updated: 5th September 2001

What about Dieting and Exercise?

What about Dieting? (or Alternate Diet)? I have no or little opinion of food dieting as a remedial aid to cancer patients. There are many of such recipes according to Chinese or western traditions. One should take the following considerations, 'Is it rational to be abstained from nutritional food while your body requires nutrition to fight the cancer cells?' And, 'Have the recipes been proven by clinical trials?' There are very few clinically proven recipes effective for cancer prevention and recovery. Certain vitamins in natural volume and anti-oxidants are known to have anti-cancer effects. It is wonderful to know that most of these beneficial items are available in our normal diets, if you eat more fresh food including fruit and vegetables. You could send your comments (tko54@hotmail.com) on such a subject.

For patients on chemotherapy, it is important to note that certain Chinese tonics / herbal medicine (e.g. ginseng) changes the amount of white blood cells. This might have a detrimental effect on your body together with the cytotoxic drug used in chemotherapy. You should talk to your doctor before taking Chinese tonics / herbal medicine while you are on chemotherapy. I did not take any Chinese medicine or any special diet during and after the treatment. I enjoy many foods including chicken and seafood. Overall I eat the same food I had prior to my treatment. With the exceptions that my preference on food has been changed because of the reduced amount of saliva, I prefer moist food like bowls of hot noodles. The only advice I could give is to eat sensibly, have less fat, less meat, less preserved food in your diet, and eat more fresh vegetables and fruits.

What about Exercise? There is something which definitely helped me through the treatment. A little exercise is a great advantage. I used to run in the morning for about 30 minutes and went to the gym regularly prior to the treatment for NPC. During the treatment, I maintained the practice with reduced vigor (because I was sick). I still do my morning exercises in order to maintain a reasonable fitness level. The sweating and the relaxation due to the rhythmic movements in running and walking have a therapeutic effect. There are some very popular morning exercises for NPC as well as other cancer patients based on breathing exercises (Chi Gong) in Hong Kong and China. I am certain that Chi Gong is very good for your well being; but I do not have the opportunities to practice it. Getting up early in the morning, greeting friends and watching the sunrise are all good for your body and soul, cancer patients or otherwise.

K T KO, Last updated: 8th September 2001

Would I be Cured? Am I going to Live?

‘Would I be cured?’ My doctor told me the seriousness of my Nasopharyngeal Carcinoma (NPC) (the stage number is out of a maximum of 5, the lower the less serious) and the probable 5-year cure rate (in %). I had a Stage IV NPC and therefore a pretty low expected cure rate (less than 50%). The staging allows the doctors to document and to compare different NPC patients under different treatments. The cure rate is the knowledge the doctors gained from treating many patients over many years. It gives the average number of survivors after 5 years. The cure rate is the overall average and does not take the patients’ individuality into account. Every one of us is different, some of us might be younger, stronger or simply more determined to survive. One should not take too much notice on the cure rate, as it is a mere statistic. It is important for us to think that we are not a percentage, we have only two outcomes - to survive the next 5-years or otherwise. Of course, being positive, you should think that you are working to stay on the good side. Indeed some of us might not respond well to the treatment. However difficult, one should remember that the treatment is a life extending process. By not going through the radiotherapy and/or chemotherapy, you are denying yourself a possibility of extending life.

‘Am I going to live?’ This is the same question as ‘How long I am going to live?’ There is no answer to this question whether you are told you are suffering from a life threatening illness or not. It is simply beyond our control, on the issue of life and death, it has never been within our control. This fact of life might be incomprehensible to a generation who have been accustomed to the illusion that they are in full control of their lives, an instant gratifying cyber generation. However ‘life is beyond one’s control’ is simply the fact and the fact that it will remain. Therefore we mortal do not have an answer to the question.

Let me borrow a fellow cancer patient / journalist’s comment on this issue:

“ ... I have no idea if the cancer will come back and I have no idea when I will die, but I never knew that anyway. I cannot find any essential difference between then and now. I decided a long time ago that there was little point wasting time and energy worrying about events I could not alter or which may never happen.”

Celia Hall, The Daily Telegraph's Medical Editor, describes how she faced having breast cancer. 17th July 2000, Sydney Morning Herald.

K T KO, Last updated: 1st September 2001

Will it Change my Life?

Better questions are to ask, ‘How much it will change my life?’ or ‘How would I see life after the treatment?’ I have yet met a patient who has not changed his/her way of life, or idea about life. Besides the little inconveniences caused by the long-term side effects, NPC has changed my attitudes to life dramatically. I could only pass on my own experiences, and you are encouraged to leave yours.

Going through the treatment of a life threatening illness is like testing your own very existence. I am fortunate to have my life extend. I see my current extended life as my second life with His generosity. However it changes the way I see life and changes the way that I would like to live the rest of my life. It also changes my ideas on success as measured by fortune and fame. Life has always existed, for all living things, in a state of perpetual impermanence. We should enjoy what we have in life, instead of marveling at what we might have lost. Therefore each day is an extra day I should be thankful for; I owe it to myself to make it a day worth living.

In a practical way, I slow down to look at things surrounding me; things that I have missed in my previous life. I am looking forward to see the sunrise of each morning because it is always unique. I stopped in my morning jog to admire the flower blossoms (as well as catching my breath). I admired the brilliances of the flowers of the Cotton

Tree at early summer, the colours and shades of the blooms from the Acacia trees in May. At work, I spent more time on tasks I enjoy, as well as tasks that I oblige to do. At home, I spent more time and attention with my little family. I live a more splendid second life. It is unfortunate but true, it took a threat of death for me to appreciate the meaning of life. Overall what I learned from this experience is to be humble in front of benevolences. In my inevitable last day (NPC related or otherwise), I know that it will be the happiness I have with my family and the warmth from my friends which flashing through my memory. I know that I would be grateful, and I know that I would be smiling.

K T KO, Last updated: 7th September 2001