National University
Cancer Institute, Singapore

Patient and Family Information

Lymphoma Patients and Caregivers Podcast Series

A member of the NUHS

This patient education podcast series is a joint collaborative project between the National University Cancer Institute, Singapore and National Cancer Centre Singapore and is supported by Takeda Pharmaceuticals Singapore.

1. Lifestyle and diet

1.1 How will my treatment affect my daily life?

There is no denying that your treatment will affect your daily life some way or another. You will want to discuss the treatment plan with your doctor and get an idea of the potential short-term and long-term side effects. Explore which are the best timings to take certain medications that might lower your cognition/energy levels. From that you can then identify specific hours and/or days of the week you feel best, versus when you experience the most fatigue, and try to plan your activities accordingly.

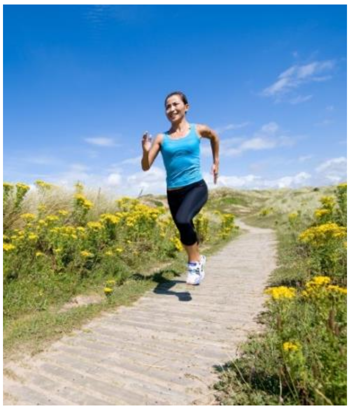
1.2 Will I be able to work, exercise and carry out daily activities?

You will be able to exercise and carry out daily activities, though it will be at a lower intensity than what you used to do. In terms of work, please discuss with your supervisor about your condition and explore options of working from home, part-time or full-time. This can help eliminate traveling to work or enable you to take a break or lie down when necessary.

Strategies to cope with fatigue/maintaining focus are:

- Write down list of priorities
- Avoid multi-tasking
- Rehearse everything
- Listen to music

1.3 How can I keep myself active and fit?



For patients diagnosed with cancer, well-meaning family members may often suggest that plenty of bed rest is important. While sufficient rest is important, appropriate amounts of physical activity during and after cancer treatment is also extremely important and has been shown in studies to be associated with many benefits including:

i) Improving strength and endurance
ii) Reducing fatigue and other side effects of chemotherapy.
iii) Improving mental wellbeing
iv) Improving bone strength and reduce risks of osteoporosis

All these lead to an overall improvement in quality of life.

Physical activity is about moving more. There are many ways for you to be physically active. This could include just getting out of bed, and moving around more in the house. It also includes doing normal activities such as housework, spending time outside with family and friends or more structured activities such as fitness classes, joining walking groups, jogging or cycling activities.

The type of activity and how much you could do will depend on factors including your cancer type and treatment given, general fitness level and your interests. It is important to do what your body feels is right for you. Some activities such as swimming might not be recommended during chemotherapy and radiation therapy, and especially when your white cell counts are low and your immunity is reduced.

In patients with bone disease, heavy lifting exercises and contact sports might have to be avoided. It is therefore helpful to seek your cancer physician, specialist nurse or physiotherapist for advice about becoming more active and the type of activities they recommend.

Some tips that many patients have found helpful include:

i) Focusing on the benefits associated with more physical activity may serve as a motivation for you to get started.

ii) Starting slowly and building up gradually on the activities is also important to avoid overtiring yourself.

iii) Set goals for yourself, but don't be discouraged if you do not achieve them initially.

iv) Try to make it a habit to be more active in your daily life. This includes incorporating of physical activity into your daily activities. For example, taking the stairs rather than the elevators or walking more around the house.

v) Try to be involved in activities with friends or in a group. They can help keep you motivated. Check also with the hospital treating you about support group events or activities that might be available.

vi) Consider keeping an activity diary and rewarding yourself when you achieve your goals.

vii) Consider also using information leaflets from sites such as the Macmillan Cancer support website, which provides practical tips on physical activity and staying active.

viii) Above all, try to do activities which you enjoy as this will allow you to stay motivated and help with your mental wellbeing.

Remember that staying active and fit should be a lifetime commitment and even after you have finished your cancer treatment, it is still important that you stay focused and continue to remain active.

1.4 What type of diet should I have to fight cancer?

It is important that you obtain adequate nutrition during your treatment and recovery

phase. Good nutrition is vital at every stage of your cancer treatment and recovery.

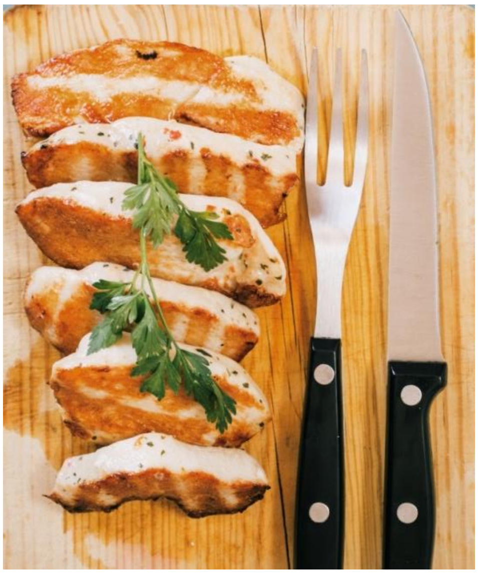
Good nutrition can help people with cancer in the following ways:

- Improve energy and strength
- Reduce risk of infection
- Better manage side effects of treatments
- Prevent deterioration in your nutrition status
- Improve quality of life
- Prevent premature discontinuation of cancer treatments

Due to the side effect of treatments, you may experience some difficulties in eating. This may decrease your intake and affect your nutritional status. The disease and treatment process can result in an increased breakdown and use of protein and fat in the body. Cancer patients undergoing treatment therefore often have increased calorie and protein needs.

Cancer and the side effects of treatments may also result in malnutrition and weight loss. Malnutrition results when the body is not getting adequate calories, proteins, vitamins and minerals.

You should therefore focus on eating well and adequately in order to optimise your nutrition and prevent unintentional weight loss and muscle mass. It is advisable for you to eat smaller meals more frequently and choose foods that are higher in energy and protein such as full cream dairy products, nuts and beans.



Supplementing your intake with high-energy, high-protein supplements can help to boost your intake and nutrition. Protein is necessary for maintenance and repair of body tissues, especially when one is undergoing cancer treatment. Protein-rich food includes chicken, fish, tofu, eggs and beans. The amount of protein you need depends on your weight, medical condition and treatment. Speak to your dietitian and let them to advise you on how much protein you need a day and how to achieve optimal nutrition.

1.5 Can I still take supplements (calcium, minerals and vitamins)?

Your natural food sources including fruits and vegetables contain a variety of nutrients and phytochemicals which cannot be replicated in the form of supplements. If you are eating well-balanced meals, you do not need to be taking multivitamins or mineral supplements. Taking certain vitamins, which are potent antioxidants, in excess may interfere with the efficacy of cancer treatments. Patients undergoing cancer treatment are advised not to take unnecessary dietary supplements unless otherwise indicated by the doctor or healthcare professional.

Calcium is important for our bone health. Although the best way of obtaining calcium is through our diet, some people may require calcium supplements as they are not getting adequate calcium in their diet. Before you consider taking calcium supplements, be sure to know how much calcium you need. Check with your doctor or dietitian if you should be taking calcium supplements.

1.6 Can I take traditional complementary medication?

We suggest that you do not take complementary medication, including traditional chinese medicine, herbal medicine or other alternative medicine, during your cancer treatment, unless your primary physician allows you to do so.

There are a few reasons for this.

Firstly, there are ingredients in complementary medicine that can interfere with the drugs treating your lymphoma. Some ingredients may give you more treatment side effects with reduced effectiveness. For example, both American and Chinese Ginseng may cause low blood sugar levels when taken with Rituximab treatment, a drug that is actually received by more than 50% of lymphoma patients.

Cordyceps, another costly and well known Chinese medicine, will interfere with steroids such as dexamethasone and prednisolone, as well as certain chemotherapy drugs such as cyclophosphamide, which is commonly used against lymphoma. If you are taking these treatments, cordyceps might reduce the efficacy of your lymphoma treatment.

Secondly, some of the complementary medications may cause harm to you, especially when taken in high doses. It may damage your liver and/or kidney and put you in danger. For example, some plants containing Aristolochia Acid have been proven to lead to kidney failure, and even cancer of the kidney, liver, stomach, and lung. These plants include but are not limited to Guan Mu Tong, Guang Fang Ji, Ma Dou Ling and Tian Xian Teng which are believed to have diuretic effects, plus offering relief of chronic cough and pain. These plants may be found in some Chinese patented drugs, without their presence being indicated.

Finally, if you intend to take the complementary medications yourself during your lymphoma treatment, you would take it without knowing whether your body really needs it or not. There are no tests that can give you this answer, and you would likely waste your money.

Therefore, in conclusion, please inform your primary physician who is taking care of your lymphoma if you are taking, or are planning to take, complementary medications during your treatment. We encourage you to have open discussions with your primary physician about the role of complementary medicine within your lymphoma treatment, so that you can be cared for to the highest standard.

1.7 Could this treatment affect my sex life?

All cancer patients and survivors are at risk for sexual dysfunction. Cancers involving sexual or pelvic organs and those undergoing treatments that affect sexual hormones appear to have the highest risk. Factors affecting sexual dysfunction include physical symptoms, emotional symptoms and interpersonal challenges. Physical symptoms include fatigue, tiredness, erectile dysfunction and feeling pain during sexual intercourse, while emotional symptoms include losing interest in sex or having a poor body image. As for interpersonal challenges, this can include having to cope with a change in relationship roles from sexual partners to caregiver-patient, or fear of not meeting one’s expectations.

Sharing the challenges or difficulties you have with your physician can allow your doctors to work with you and your partner to come up with strategies to manage. This will also allow your physician to attend to comorbidities that could worsen sexual functions. Your physician will also have the opportunity to discuss with you the duration of sexual dysfunction so as to better address this issue.

1.8 Could this treatment affect my ability to become pregnant or have children? If so, should I talk with a fertility specialist before cancer treatment begins? If I'm a man, should I bank my sperm? How much will it cost?

Yes, cancer treatment may potentially affect one's ability to have children. However, there are multiple factors that can affect fertility. This includes:

- Fertility status before treatment of either partners or the type of treatment received.
- If chemotherapy is received, it also is dependent on the intensity and type of chemotherapy.
- If it is radiation therapy, it depends on where the radiation therapy is given.

If you are a man, fertility preservation is more straightforward and would involve banking your sperm. For a woman, it is a bit more complicated and there are different options. A consult with a fertility specialist will be necessary to see what works best for you. The cost would depend on what method of preservation is used, where it is done and if subsidies are available.

Speaking with a fertility specialist before starting treatment is ideal. But it may depend on how urgently your treatment must be started. In life-threatening or emergency situations, there may not be time to do so.

Under normal circumstances, speaking with a fertility specialist to know your options would be the best.

2. Patients and caregivers wellness

2.1 How can I cope with anxiety and depression of diagnosis and relapse?

Being diagnosed with cancer or the recurrence of cancer can be devastating. It leaves us in a state of shock and numbness, which can then turn into dread and despair. It seems like our whole world is falling apart. We imagine the very worst and may feel at a loss of what to do. These feelings are difficult to experience, but are normal reactions when we receive bad news. The intensity of these initial feelings will also lessen with time.

So how can we cope? First of all, realise that when you are in a state of shock, you may have difficulty focusing and absorbing information given to you. Patients often report feeling that the initial phase of diagnosis and treatment seem to pass by in a blur. Be careful not to overwhelm yourself with too much information all at once.

Once the shock wears off, you may feel more ready to look for answers and to start treatment quickly. However, it may take some time for your doctor to carry out the necessary investigations before proceeding with the right treatment. This waiting period may cause heightened anxiety as some people find it hard not knowing exactly what to expect. Recognising that it may take some time can help you to manage your anxiety about uncertainty better. You may not have much of an appetite or feel like doing anything. However, it is important to continue to take care of yourself by having your meals and getting sufficient rest.

The right kind of support at this time is also crucial. Choosing whom to tell and lean on for support is important. Some people may hesitate to confide in family or friends for fear of burdening them. However, research has shown that reaching out to others when stressed is an effective way of improving our mood. Accepting help also gives those who care about you a sense of making a contribution at a difficult time. If you have trouble finding someone suitable, you can seek out professional support. Ask your doctor for a referral to a social worker, psychologist or counsellor.

Lastly, whilst the tendency is to associate cancer with doom and gloom, it also offers an opportunity for personal growth. Oftentimes, facing the possibility of death allows us the opportunity to assess our lives and to realize what is truly important to us. Hence, even in the midst of sadness and loss, we can experience fulfilment and joy. We may not be able to add more days to life, but we can certainly add more life to days.

2.2 How can I manage physical and emotional well-being?

Being diagnosed with Lymphoma is probably something that would come as a shock to most of you. It is not an easy period of time, you may have to come to terms with your disease and there will be many changes that you will experience. For example, you may have to change your diet or perhaps even your daily routine. This may not be simple, and we are here to tell you what won’t change, what might change and practical ways on how to cope emotionally.

Let’s start with things that won’t change. While the future may seem bleak at this point in time, remember that you don’t change. Your personality, your goals, your strengths – they don’t change. The things that used to make you happy in the past will still make you happy now. Your network of friends and family that care for you are still the same. Your core values, your spiritual believes, they remain the same. Your coping mechanisms remain the same. Think of a time that you went through a difficult time and came out triumphant, and then think about how you coped with it. You know yourself best, and those are the coping mechanisms that will help you through this trying period as well.

While your personality and your sense of self do not change, there would be changes to your body that you might experience. You might experience a loss of health and change in body image; this may affect you most if you have always been healthy with no medical issues. You might experience the loss of independence or financial losses that may come about because you are not able to work as you once were. You might experience a loss of fertility or sex drive during this period of time. Do remember that most of these changes are temporary. Please speak to your doctor if you are very worried about this, and they will do their best to address this.

There are some practical methods that can help with your emotional well-being during this trying period. Besides relying on yourself and coping mechanisms that you had previously used, you should also try to build up a network of friends and/or whom you trust and that you can rely on. Confide in them and let them know about what is bothering you. Keep yourself occupied. You would have certain interests in the past that you might still be able to enjoy or perhaps could be modified to suit your current needs. Discuss this with your doctor if you are not sure if you can pursue your interest – if it is not appropriate, she or he would suggest a compromise or an alternative during the period of time that you are undergoing treatment.

Other avenues or supports that are also available for you would include that of your Doctor, Medical Social Worker or Lymphoma Support Groups. Do reach out to them if you need more help with coping, or if you feel that you are feeling lost emotionally. Everyone will be willing to help you in whatever way possible.

To conclude, remember that this period of time is temporary. It will end. However hard it may seem, you do have the resources to maintain a good emotional well-being through the period of your treatment. So, hang in there, grit your teeth, and remember the light is at the end of the tunnel!

To listen to podcast series 2, scan the QR code or visit www.ncis.com.sg (http://bit.ly/2x9ehRD) >

3. Financial and emotional support

3.1 What kinds of assistance are available for me? What cancer support services are available?

Meeting your psychosocial, emotional and practical needs are important parts of holistic cancer care. These needs are addressed in various forms such as individual and family counselling, support group meetings, and psycho-educational workshops.

Individual and family counselling seek to enhance your level of personal well-being and coping ability. A medical social worker, psychologist or counsellor works with you on specific issues, such as adapting to cancer diagnosis and treatment, relationship matters, and/or mood changes.

Participating in support groups is a way to seek support from fellow cancer patients, survivors and caregivers. Members of such a group often share at least one commonality, such as living with a particular cancer type or being from the same ethnic group. Learning from each other’s experiences and participating in common activities are often useful for improving and enriching your psychological and social well-being.

Attending psycho-educational workshops allow you to learn about knowledge and skills related to cancer care from the experts. These topics include, but are not limited to, diet and nutrition, exercises, and tips on self-care.

At times, you may be referred to non-hospital resources or agencies for further support, especially to meet practical needs. For example, if you require financial assistances to meet your daily needs, you may be referred to the Social Service Office in the community near your home. Or if you require nursing or home hospice care services to support your care at home, community healthcare partners will be asked to come on board.

In summary, there is a range of supportive services and programmes to meet different needs. You can access these resources by speaking with your doctors, nurses, medical social workers, psychologists or counsellors at your respective healthcare institutions.

3.2 Befriending someone with cancer – Lymphoma support group

An official national lymphoma support group was formed in 2017, driven by a group of passionate lymphoma survivors. Prior to this, talks were organized for lymphoma patients, survivors and their caregivers on an irregular basis.

There are currently two platforms for the support group, one is a private group on Facebook and the other one is a WhatsApp group. Inside this group, there are patients and survivors from private sectors and different public hospitals, as well as caregivers and healthcare professionals.

Regular talks are organized twice a year, one in March and one in June, as well as ad-hoc gatherings organised by our members. For the regular talks, professionals with wide-ranging expertise are invited to speak, alongside survivors and caregivers who share their opinions and experience in caring for the overall well-being of lymphoma patients and survivors.

There are several reasons you may wish to consider joining the support group.

- You may find it a safe place to share your experiences and connect with other people who are navigating the same challenges related to your lymphoma.

- The support group is run by healthcare professionals and survivors with expertise, designed to help patients and caregivers to cope with adjusting to lymphoma, emotionally, socially and physically.

- Many scientific studies have shown that support groups can reduce anxiety and stress, emotional distress, fatigue and pain, as well as improve mood, self-image, ability to cope with stress and feelings of control.

- Joining a cancer survivorship programme can help to equip you with the resources and support to navigate your new post-treatment life.

Please feel free to contact us if you are interested to participate in the lymphoma support group. Please email sg.lymphoma@gmail.com or call the CancerLine (9722 0569) for more information.

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Appointment Line: (65) 6773 7888

CancerLine: (65) 9722 0569

Lymphoma Support Group: sg.lymphoma@gmail.com

Website: www.ncis.com.sg

Information is correct at time of printing (October 2018) and subject to revision without prior notice.