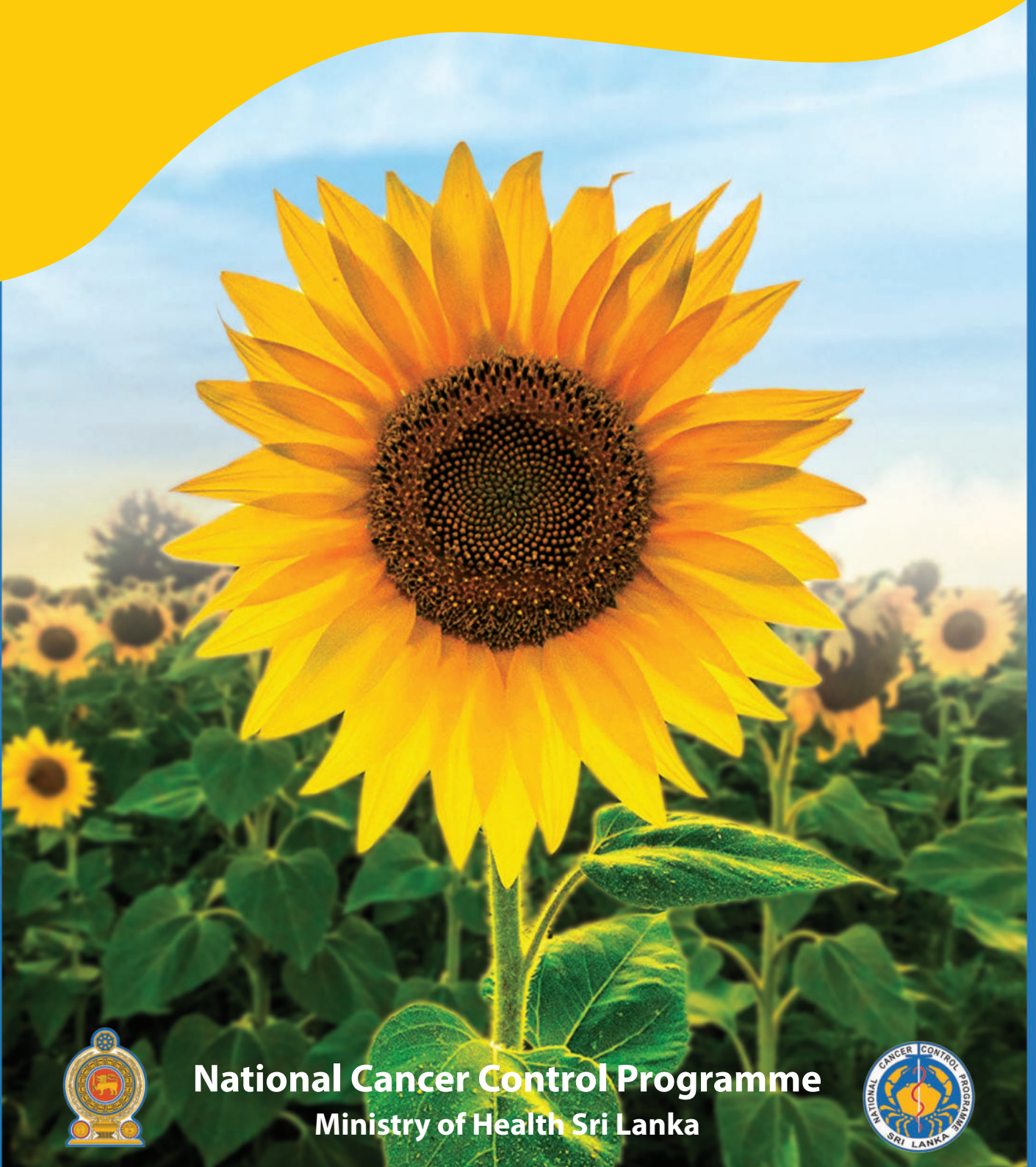


Survivorship Care for Cancer Patients

A Guide for Health Care Professionals



National Cancer Control Programme
Ministry of Health Sri Lanka



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2023



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Message from Deputy Director General Non – Communicable Diseases



In Sri Lanka, with the demographic and epidemiological transition, the need for cancer care including cancer survivorship care services also continues to grow. The number of cancer survivors is expected to increase with the early detection and comprehensive treatment pathways and their health needs must be addressed by the health system. Therefore, cancer survivorship care is identified as an essential component in continuum of cancer care.

National Cancer Control Programme published the National Strategic Plan on Prevention and Control of Cancer in Sri Lanka (2020-2024) targeting the strengthening of cancer care services at all levels of health care system from the community level upwards. Availability of skilled multi-disciplinary human resources for delivery of cancer survivorship care services including primary healthcare is also identified as an important strategic direction.

This guide is developed to provide orientation and guidance on cancer survivorship care for health care professionals including primary healthcare workers and I appreciate the leadership of National Cancer Control Programme taken to develop the guide. I would like to thank all the experts for their technical inputs despite their busy schedules and the extended partnership of World Health Organization for the development of cancer survivorship care services in Sri Lanka.

Dr. Champika Wickramasingha

Deputy Director General (Non-Communicable Diseases)
Ministry of Health

Message from Director National Cancer Control Programme



The need of cancer survivorship care services in Sri Lanka continues to grow owing to the rising prevalence of cancers. Survivorship care is a part of cancer care which provides a continuum of care for cancer patients from the time of diagnosis of their disease to the end of their lives.

With the aim of strengthening cancer survivorship care services in Sri Lanka, National Cancer Control Programme developed this survivorship care guide for healthcare professionals to address the knowledge gap among them. Therefore, this guide will be useful for them to improve the health and well-being of cancer survivors by providing a continuum of care.

I thank all the experts who have contributed as resource persons to complete this activity. I specially appreciate the partnership provided by the World Health Organization for this task.

I hope that all healthcare providers will utilize this guide effectively to improve cancer survivorship care services in the country.

Dr. Eshani Fernando

Director

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Special Acknowledgement for Guidance and Assistance

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Preface

Cancer survivorship is defined as *“The health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social and financial effects of cancer that begin at diagnosis and continue through treatment and beyond. The survivorship experience also includes issues related to follow-up care (including regular health and wellness checkups), late effect of treatment, cancer recurrence, second cancers, and quality of life. Family members, friends and caregivers are also considered part of the survivorship experience” (National Cancer Institute at the National Institute of Health, 2019).*

In Sri Lanka, the prevalence of cancer is increasing. Therefore, the need for survivorship care is growing due to the increasing numbers of cancer survivors living years beyond their cancer and the rising numbers of new patients diagnosed with cancer. Therefore, Ministry of Health, Sri Lanka affirms the importance of integrating cancer survivorship care into all levels of healthcare as an essential component of the continuum of cancer care. Furthermore, it has been identified as one of the strategic directions in the National Strategic Plan in Prevention and Control of Cancer in Sri Lanka (2020-2024).

Cancer survivors need ongoing care to address issues such as complications in multiple organ systems, psychological disturbances, spiritual wellbeing, social relationships, financial well-being etc., that can lead to functional limitations and reduce the quality of life in cancer survivors. The lack of clinical time available to address cancer survivors’ needs, lack of provider training to address these needs and patients’ inability to follow the care plan are some contributing factors for gaps in cancer survivorship care. Therefore, multiple strategies for strengthening care delivery are needed to improve patient outcomes and to overcome workforce constraints including knowledge gaps.

Improving knowledge among healthcare providers will enable to deliver cancer survivorship care not only at the oncology units but also in other health settings including primary healthcare. This will improve access to cancer survivorship care and survivor well-being, as well as reduce costs for healthcare systems and provide financial risk protection for patients’ families, by reducing dependency on specialized units. Therefore, this document will serve as a guide for healthcare professionals at all levels of healthcare in the country.

Chapter One

Introduction to Cancer Survivorship Care

A person who has had a cancer diagnosis is often called a “Cancer Survivor.” When people talk about “survivorship,” they are usually referring to navigating their life experiences and challenges resulting from their cancer diagnosis.

Definitions of cancer survivorship

“In cancer, survivorship focuses on the health and well-being of a person with cancer from the time of diagnosis until the end of life. This includes the physical, mental, emotional, social, and financial effects of cancer that begin at diagnosis and continue through treatment and beyond. The survivorship experience also includes issues related to follow-up care (including regular health and wellness checkups), late effect of treatment, cancer recurrence, second cancers, and quality of life. Family members, friends, and caregivers are also considered part of the survivorship experience” (National Cancer Institute at the National Institute of Health, 2019)

“An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience” (Clinical Oncology Society of Australia, 2016)

Survivorship means different things to different people, but it often describes the process of living with, through and beyond cancer.

Who is a cancer survivor?

- **Cancer survivor** is referred to any person who has been diagnosed with cancer and who is alive.
- Whether being cured or not, cancer survivors do experience late and long-term effects of treatment, emotional distress, and the potential of tumour recurrence.
- It is a challenge to the healthcare system of the country which has to maintain their proper follow-up care as well as their quality of life. In other words, it is important to see how long they can live after cancer diagnosis and how well they can expect to live after cancer diagnosis.

- No matter how it is defined, survivorship is different for different people. Some people dislike the word “survivor”. Everyone has to find their own path to traverse the challenges and changes that arise as a result.

Cancer survivorship in Sri Lanka

- The annual incidence of cancer patients in Sri Lanka is around 37,000 (National Cancer Registry, 2020). Hence, there are many cancer survivors living in Sri Lanka.
- The number is expected to grow due to the increase in cancer incidence and the increase in life expectancy following definitive cancer treatment.
- However, most cancer survivors in Sri Lanka do not receive adequate survivorship care services.

The most common cancers among females in Sri Lanka

1. Breast Cancer
 2. Thyroid Cancer
 3. Colorectal Cancer
 4. Uterine Cancer
 5. Ovarian Cancer
- (National Cancer Registry, 2020)

The most common cancers among males in Sri Lanka

1. Lip, tongue and mouth cancer
 2. Trachea, bronchus and lung cancer
 3. Colorectal Cancer
 4. Oesophageal Cancer
 5. Prostate Cancer
- (National Cancer Registry, 2020)

When does survivorship care start?

- Primary treatment is the first course of therapy provided with the intention to cure cancer. When the primary treatment is completed, long-term survivorship care is introduced and maintained. An organized plan for survivorship care should be developed by the time primary treatment ends.

Who should provide survivorship care?

- Survivorship care can be provided by specialists and primary healthcare providers.
- These multidisciplinary teams of care providers consist of various care disciplines including doctors, dental surgeons, nursing officers, public health nursing sisters, public health nursing officers, pharmacists, nutritionists, physiotherapists, speech therapists, occupational therapists, counsellors, social service officers/ workers, etc.
- Optimally a designated individual should be responsible for coordinating survivorship care. In Sri Lanka, the oncology team is identified as the coordinating unit for cancer survivorship care.
- It is viewed as a shared responsibility.
- Although the cancer survivors should be included as informed care partners in survivorship care, the primary responsibility of coordinating care should be with healthcare workers.

Challenges of providing cancer survivorship care

- In Sri Lanka, around 37,000 new cancer patients are diagnosed every year (National Cancer Registry, 2020). However, there is no database to identify the number of patients who are currently living with a cancer diagnosis (prevalence) in Sri Lanka.
- Many of these cancer survivors have unmet needs (e.g. physical, psychological and social issues) at the end of treatment (Burg et al., 2015; Girgis et al.,2013)
- Some experience the consequences of treatment given for cure or palliation.
- The method of providing survivorship care should be based on outcomes, giving priority to address unmet needs.
- Survivorship care is still not identified as an important aspect of care by healthcare providers in Sri Lanka.
- In Sri Lanka, lack of available resources to support cancer survivors' basic needs (eg: financial facilities) is a major challenge.
- Lack of knowledge among cancer survivors and their family members/caregivers on the treatment procedures, prognosis and support systems in survivorship care is another unaddressed issue.

Chapter Two

Components of Survivorship Care

Overview

Survivorship care commences at the point of diagnosis and it has three components: active care, intermediate care and long-term care.

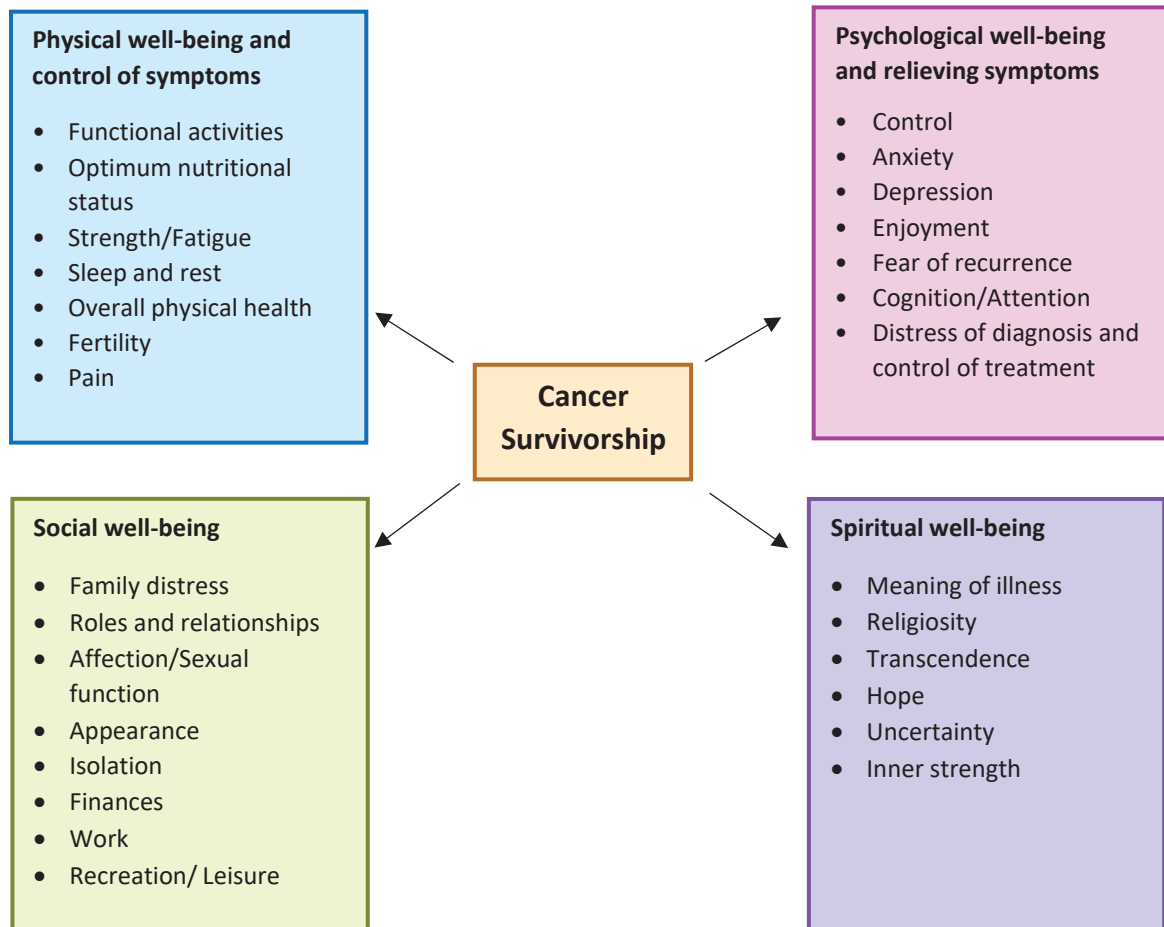
As the oncology team is responsible for active management, it is beyond the scope of this guide. Therefore, this guide includes only the intermediate and long-term management of a cancer survivor.

- Cancer care does not always end when active treatment finishes. When cancer treatment ends, the patient needs to be monitored by the oncology team for managing any side effects and to ensure early detection of recurrence when and where appropriate.
- Hence, the follow-up care plan may include regular physical examinations and medical investigations during the forthcoming months/years.
- The survivor may have many concerns regarding his / her future health. Therefore, adequate information, support and care have to be given to the patient, the family and the caregivers throughout the process of cancer treatment and when the treatment ends, throughout the follow-up care.
- The patient has to be followed up at the oncology clinic as well as at the patient's locality with the primary healthcare team.
- Participating in follow-up care of the patient by the primary healthcare team is essential to maintain good physical, mental, social and spiritual health of the patient. It also helps the cancer survivors feel in control when they transit back into their normal lives.

Essential components of survivorship care

1. **Prevention** of cancer recurrences, new cancers and other late effects.
2. **Surveillance** for distant cancer spread (metastasis), local cancer spread (recurrence), second cancers and for assessment of medical and psychosocial late effects.
3. **Intervention** for consequences of cancer and its treatment
 - Eg:
 - Malnutrition, sarcopenia and other disease-specific nutrition issues
 - Medical problems such as lymphoedema
 - Physical symptoms including pain & fatigue, psychological distress experienced by cancer survivors and their caregivers
 - Concerns related to employment, insurance and disability, etc
4. **Coordination** between specialists and primary healthcare providers to ensure that all the healthcare needs of the survivors are met.

Quality of life model needs to be applied to cancer survivors



(Adapted from Journal of Cancer Survivorship, 2007)

Survivorship care plan

A survivorship care plan is a detailed, written plan provided after active treatment ends and is customized to an individual patient's needs. This plan should be drawn up by the oncology unit together with the patient, to make sure it meets the patient's needs.

Every survivor should be offered a holistic needs assessment and associated care plan.

- **At diagnosis and at the end of treatment**
- **When the need arises or patient requests a reassessment and a revised care plan**

Elements of a survivorship care plan

- Diagnosis summary
 - Details of the cancer diagnosis
 - Diagnosis date
 - Type of cancer
 - Location
 - Stage
 - Histology
- Names and contact information of the care providers and treatment facilities
- Treatments administered
 - Chemotherapy/Biotherapy — regimen, drug, dose, cycles, clinical trial information
 - Radiation — type, dose, site
 - Surgery — procedure
- Follow-up plan
 - Specific recommendations for ongoing care
 - Schedule of visits with oncology specialist
 - Surveillance testing for recurrence
- Identify and manage long-term and late effects
- Health promotional strategies
 - Dietary modifications
 - Regular exercise
 - Smoking cessation
 - Alcohol abstinence
- Mental wellbeing

Role of healthcare professionals in survivorship care

1. Discuss the survivor's needs

The holistic needs assessment should be done to assess the survivor.

It should include:

- Physical problems
- Psychological problems
- Spiritual problems
- Financial problems
- Social problems
- Other practical concerns (including caregiver issues)

2. Follow the treatment summary and follow-up plan

- A treatment summary and follow-up plan are provided for reference for the primary healthcare team.
- The treatment summary is given to the patient at the end of treatment by the specialized unit where the patient is treated and it should include a summary of all the treatments received by the patient during that time.
- Further to that, follow-up plan of the patient is given and it includes signs and symptoms of which the health care provider as well as the patient should be aware.
- The signs and symptoms such as possible consequences of cancer and its treatment, signs of recurrence, other important information, etc. are clearly mentioned.

The treatment summary should be provided to the patient, to be shared with the primary healthcare medical staff

- At the end of a defined treatment or series of treatments
- When being discharged from regular follow-up

3. Identify a main contact

- It is important to identify a main contact person for the benefit of the patient, the cancer treatment unit, primary health care medical staff and the other health staff.

The details of the contact person must be provided

- To the primary health care medical staff
- To the oncology unit and the others whom the patient considers as necessary.

4. Identify and make early referrals for consequences of cancer and its treatment

- Cancer and its treatment have far-reaching consequences.

Information on possible consequences of cancer, it's treatment and the steps to follow should be provided routinely to all cancer patients.

- Written information should be provided to support the information given verbally.

5. Encourage people to talk about their emotions

- Cancer diagnosis has a significant emotional impact on the patient.
- A significant proportion of patients may need professional support for mental health issues such as anxiety, depression, stress, adjustment problems, grief, denial, guilt, etc.

Use a recommended and validated Psychological Distress Assessment Tool to help identify psychological distress, anxiety or other psychological supports needed

- For example, DASS-21 scale (Depression, Anxiety, Stress Scale -21)
- If a psychological distress score is recorded, the problem should be discussed with the patient and he/she should be referred to psychological support services.

6. Promote a healthy lifestyle

- The adoption of a healthy lifestyle is very important for those who have had a cancer diagnosis.
- It is important to assess the information needs of the patient such as information about cancer and its treatment, side effects of treatment, available supportive services, other information needs, etc.
- The patient and the family must be referred to get the required information by the primary care physician.

Patient should be provided with information to help them make healthy life choices

- **Diet**
 - There are beneficial effects of diet on preventing cancer recurrence, mortality and morbidity.
 - Nutritional issues during or following treatment include: **
 - ✓ Weight loss or gain
 - ✓ Changes in body composition (eg: loss of muscle mass, particularly due to eating difficulties including swallowing problems or a limited capacity for food).
 - ✓ Long-term consequences (eg: changes in bowel habits for those who have had pelvic radiotherapy, short bowel syndrome for those who may have undergone bowel resection)

- Patients are provided with dietary advice with a referral to the medical nutrition unit as required.
- General recommendations
 - ✓ Maintaining a healthy BMI with lean weight is important
 - ✓ Be alert with the portion size of the main carbohydrate portion of the diet
 - ✓ Incorporate more complex carbohydrate food (eg: whole grain cereals, variety of local yam, etc)
 - ✓ Limit refined sugars
 - ✓ Incorporate healthy fats into the diet (eg: a handful of mix of nuts per day, avocado)
 - ✓ Adequate protein intake is essential to maintain a good lean body mass
 - Incorporate animal proteins (eg: Fish, egg, lean meat such as chicken)
 - Limit red meat consumption
 - Include plant proteins to the meals (eg: pulses, soya products, etc)
 - ✓ Having a variety of vegetables and fruits is important to improve the fiber content and micronutrient content of the diet (eg: choosing locally available and seasonal varieties with a low cost to achieve a complete balanced diet)
 - ✓ Adequate hydration is important (eg: water, tea, coriander water, etc)
 - ✓ Unnecessary use of nutrition supplements is discouraged but when necessary, should be prescribed by a nutrition physician.

**** Please remember above are general recommendations and they might change according to underlying bowel pathologies or other comorbidities. Therefore, timely referral to a medical nutrition unit is important.**

- **Physical activity**

- People should be encouraged to maintain or increase their level of physical activity both during and after treatment.
- Need for support to increase or maintain their physical activity should be assessed.
- Physical activity results in improvement in quality of life, fitness and alleviation of symptoms related to cancer and its treatment
- It can improve post-chemotherapy T- cell recovery.
- It reduces cancer recurrence, incidence of second cancers and reduce mortality due to cancer and other causes.
- People living with and beyond cancer should exercise to the same level as the general population for health benefits.
- A combination of cardiovascular and muscle strength training has an important additional benefit.

- **Mental wellbeing**

- People should be encouraged to maintain happiness, inner peace and manage stress effectively (relaxation, mindfulness, etc.)

- **Smoking cessation**

- Tobacco smoking is one of the main causes of preventable morbidity and premature death in Sri Lanka.
- All current smokers should be asked about their smoking habits at key pathway points
 - eg: At diagnosis
 - After surgery
 - During follow up visits
 - At primary healthcare services

- **Refraining from betel, areca nut and tobacco chewing**

- **Abstinence of alcohol**

7. Stratified follow up

The current model of survivorship care is specialist driven. However, different models have been studied to provide survivorship care such as models led by primary-care providers, care shared between oncology specialists, etc.

Stratified self-managed follow-up gives back control to people living with and beyond cancer, by ensuring that they are able to access specialist care when it is required and have the confidence to make decisions about their own health and well-being (Jefford et al., 2022)

- Implementing stratified follow-up can improve after-care as it offers a personalized approach, promotes supported self-management and allocates more resources to those in greatest need.
- This reduces anxiety of attending routine appointments and less interference in their day-to-day life.
- For self-management to be effective, cancer survivors and their primary healthcare providers need to be given the right information about the signs and symptoms of recurrence and clear pathways to follow if they have any concerns.

8. Encourage survivors to share their experience

- Sharing the experience of cancer survivors can be beneficial to the patients themselves, caregivers and others who have cancer experience.
- People living with and beyond cancer should be offered information on local support groups and where they can access information on sharing experiences.
- Whenever possible, health and well-being events should be conducted with cancer survivors.

9. Watching for recurrence

- One goal of follow-up care is to check for cancer recurrence. To help find the occurrence of a recurrence, specific questions need to be asked related to the cancer and the patient's health.
- A thorough physical examination needs to be done during follow-up visits.
- Depending on the cancer, the recurrence may happen months or even many years after the original cancer was treated.
- If a recurrence is suspected, the survivor needs to be attended to the oncology unit to confirm the recurrence.
- After confirming the recurrence, the oncology team will review the situation and discuss with the patient on treatment options.

10. Managing late and long-term side effects

- Side effects are usually expected during or after treatment but some of the side effects may linger for months or even years after treatment.
- Other diseases, the survivor may have such as diabetes or heart disease may worsen due to cancer treatment.

Some of the possible long-term side effects of cancer treatment are described in Chapter 3.

11. Support living with advanced cancer

Even though advanced cancer cannot be cured, it can often be effectively controlled. Therefore, it is important to realize that incurable does not mean untreatable. Proper cancer care often keeps the cancer under control and maintains quality of life. Palliative care has an important role in the management of advanced cancers. Nutrition interventions according to the stage of palliation can be carried out to ensure the quality of life, therefore referral to a medical nutrition unit is important.

12. Be alert for the development of secondary or subsequent cancers

Due to various reasons, survivors may develop cancer recurrence or secondary cancers. The reasons may be previous cancer treatment such as chemotherapy and radiotherapy, alcohol and tobacco use, genetic risk factors, environmental risk factors such as air pollution, chemical exposure, etc.

- To identify cancer recurrence or subsequent cancers as well as the late and long-term side effects of cancer therapy as described above, the oncology team needs to develop a follow-up plan after discussing with the cancer survivor.
- Primary care physicians should monitor the survivor's needs and whether the follow-up plan is properly adhered to.

13. Keeping a personal health record

- Cancer survivors must be requested to keep the information about the disease and the treatment provided to the survivor. This should be prepared by the Consultant Oncologist and the team after discussing with the patient.
- This information must be shared with the Primary Care Physician who is currently following up the survivor.
- In the meantime, the survivor must be advised to review the care plan himself / herself.
- Some survivors wish to prepare other documents related to medical care such as the advance directive which includes their short-term and long-term medical wishes.
- In Sri Lankan context Shared Care Clinic Record (H-1314) can be used as the personal health record for cancer survivorship care.

The following details should be included in the follow-up care plan.

- Investigations and examinations to detect recurrence or metastasis of cancer
- A planned investigation schedule
- Care and management plan to detect any long-term side effects
- Psychosocial support and counselling
- Referral for financial support (if needed)
- Referral and coordination with Oncologists and other specialists such as Cardiologists, Endocrinologists, Psychiatrists, etc.
- Health education on healthy behaviors such as taking a nutritious diet, physical exercise, etc.
- Advices on family-based care (eg: child's education)
- Advices on identification and management of late and long-term effects of cancer

14. Communication with the oncology team

- The primary care physician must communicate with the oncology team throughout the care process from the moment of diagnosis, during and after treatment.
- It is important to include the patient's caregiver, and the family members throughout the survivorship care of the patient.

Chapter Three

Managing Late and Long-Term Side Effects

Side effects are usually expected during or after treatment. But some of the side effects may linger for months or even years after treatment. Other diseases the survivor may have, such as diabetes or heart disease may worsen due to cancer treatment.

1. Attention, memory and thinking problems

- People who have been treated for cancer may have cognitive impairments such as thinking problems, difficulty in concentrating and remembering, multi-tasking, etc.
- These symptoms can be seen especially in those who have CNS cancers and those who experience related fatigue.
- If you notice symptoms of cognitive impairment, they should be referred to the oncology unit for further management of those issues.
- The cancer survivor can be advised to:
 - Keep a notebook or planner to note the problems and experiences
 - Engage in daily exercise
 - Engage in meditation, mindfulness, yoga and other relaxation activities
 - Have adequate sleep

2. Bone, joint and soft tissue problems

- Cancer survivors who received chemotherapy, steroids and hormonal treatment may develop osteoporosis.
- If signs and symptoms of osteoporosis are noticed, the patient should be referred to the oncology unit for further management.
- The patient should be advised to have regular physical activities such as walking and to add food rich in calcium and vitamin D to their meals.

3. Digestion and swallowing problems

- Chemotherapy, radiation therapy and surgery may affect the patient's food digestion.
- Chronic diarrhoea may affect digestion and absorption.
- If the patient has digestion problems, those should be addressed and referred to the medical nutrition unit for further advice and support.
- Patients can have swallowing problems which may affect nutritional as well as social relationships. (eg: Reluctance to have meals with others due to swallowing problems.)
- These issues need to be addressed by referring to speech therapy, nutrition clinic and psychiatry clinics.

4. Oral and dental problems

- Many cancer treatments may result in side effects that affect a person's mouth, teeth and salivary glands causing difficulties in eating, talking, chewing, swallowing, etc.
- Oral care can be provided with the support of general dentists and specialized dental health professionals.

5. Fatigue

- Cancer-related fatigue is the most common side effect of cancer treatment.
- Fatigue is identified as the persistent feeling of physical, emotional and mental tiredness or exhaustion. Cancer-related fatigue is not relieved by sleep or rest.
- It sometimes remains months or even years after cancer treatment.
- It can occur due to cancer itself, cancer treatment, anaemia following cancer treatment, chronic pain causing less sleep, poor nutrition, certain medications such as analgesics, lack of exercise, hormonal changes, etc.
- Fatigue is one of the symptoms of depression, anxiety, or any other psychological conditions.
- Fatigue may seriously affect the cancer survivor's day-to-day activities and even their occupation. Therefore, it is important to address this, as there are certain methods to alleviate fatigue.
- The underlying cause for fatigue such as anaemia, depression, nutritional deficiencies needs to be identified and treatment should be commenced. If there is lack of sleep due to chronic pain, pain medications should be provided.
- It is recommended to introduce physical exercise, psychological therapy, healthy and balanced diet and adequate sleep to improve fatigue.
- For emotional support, the survivor should be referred to the mental health unit of the nearest hospital for psychological counselling and treatment.

6. Cardiac problems

- Cardiac problems are often caused by radiation therapy to the chest, specific chemotherapy and targeted therapies.
- The problems that can occur could be damage to the cardiac tissues, blocking or scarring of the blood vessels of the heart, cardiac rhythm abnormalities, and damage to the cardiac valves.
- If any cardiac problems are suspected by the primary health care physician, the survivor should be referred to the oncology unit or the cardiac unit for further management.

7. Endocrine problems

- Some types of cancer treatment may affect the endocrine system, eg: who received radiation therapy to the head and neck may have lower levels of thyroid hormone levels.
- Oophorectomy, chemotherapy, hormonal therapy, radiation therapy to the pelvic area may cause premature menopause in females or irregular menstrual periods.

- In some younger females, menstrual periods may restore but in those who are above 40 years, the menstrual cycles may not be restored.
- Those who have concerns related to their reproductive health as well as those who have expectations to have children need to be referred to a gynaecology clinic for further management.

8. Lung problems

- Those who received radiation therapy, chemotherapy or surgery to the lungs or the chest may experience lung problems due to pneumonitis, lung fibrosis or complications of surgery to the whole or part of a lobe of the lung.
- Therefore, those cancer survivors need to be monitored for lung problems at the oncology unit or relevant chest clinics.

9. Lymphoedema

- Lymphoedema is caused by a blockage in the lymphatic system due to the damage to the lymph nodes of the cancer survivor.
- Often lymphoedema occurs in an arm or a leg, eg: patients who are treated for breast cancer may develop lymphoedema in the arm; patients who are treated with pelvic and inguinal radiotherapy may develop lymphoedema in the leg.
- Lymphoedema may occur in other parts of the body such as below the chin and sometimes inside the mouth in patients with head and neck cancers treated with radiotherapy.
- Sometimes lymphoedema may settle when the lymphatic flow becomes normal, but if lymphoedema becomes chronic, it should be managed properly.
- The information needs to be provided from the oncology unit initially to manage lymphoedema of arms and legs. If necessary, the cancer survivor needs to be referred to the oncology unit for further management.

10. Peripheral neuropathy

- Peripheral neuropathy can occur due to damage to the peripheral nervous system by radiation therapy, some types of chemotherapy or by the cancer itself.
- The person may have numbness, tingling sensation or muscle weakness usually in the hands or feet.
- People with autonomic nerve damage may develop dizziness when sitting or standing up, and may develop urinary or bowel incontinence, blood pressure changes and irregular heartbeat.
- If those symptoms develop, the primary healthcare physician needs to evaluate the possibility of other causes for the symptoms such as diabetes.
- Advices need to be provided to prevent cuts and injuries to the affected part.
- For further management, the person needs to be referred to the oncology unit as there are medications available to reduce sensory symptoms and pain, as well as occupational therapy for them.

11. Urinary problems

- Some cancer treatments, including radiotherapy, some types of chemotherapy and surgery may cause urinary and bladder problems.
- Urinary tract infections, radiation cystitis and urinary incontinence are some of the common urinary problems.

12. Other physical effects

- Cancer treatment can change a person's body image and function. For example, if a person's arm or a leg is amputated the person may experience phantom limb pain (pain of the limb or arm appears to be coming from the limb/arm which was removed).
- Those who have lost a limb due to cancer and those who have phantom limb pain like symptoms need to be referred to the rehabilitation services available.

13. Sexual and reproductive health problems

- Sexual and reproductive health problems in cancer survivors are caused by Radiotherapy, Chemotherapy, surgical intervention or the cancer itself.
- The most common sexual problems include loss of sexual desire in both male & female survivors, erectile dysfunction in male survivors, and pain with sexual activity in female survivors.
- When the cancer survivors are suffering from sexual dysfunction, the primary care physician must treat the reversible factors. eg: female survivors can be offered vaginal lubricants and moisturizers for vaginal dryness, etc.
- When necessary, the survivors can be referred for sexual counselling and specialized management. eg: premature menopausal symptoms in female survivors, erectile dysfunction in male survivors, etc.
- If the survivors diagnosed in their reproductive years are suffering from infertility, they must be referred for specialized treatment for infertility/subfertility following oncology advice.

14. Psychiatric and psychological disturbances

- Cancer survivors often experience a range of positive and negative emotions; sense of gratitude to be alive, relief, fear of recurrence, anger, guilt, depression, anxiety, isolation, etc.
- The family members of the cancer survivor and the caregivers may also be going through similar emotions during the process.
- If there is difficulty in coping with those negative emotions, the cancer survivor and the loved ones must be advised to seek support from the mental health unit/clinics in the hospital/community.
- Patients and caregivers should be regularly assessed for psychiatric disorders such as anxiety, depression, stress disorders, suicidal ideation, etc.

Chapter Four

Challenges Faced by Survivors and Support for Coping

A cancer survivor may suffer due to various issues related to physical health problems, mental health issues, spiritual concerns, social issues, financial issues, fear of recurrence, etc.

Therefore, the primary healthcare team should be more vigilant about the evidence of all health problems in the survivor. If there is any concern, it is very important to refer him /her for the relevant specialized unit or supportive services for further management.

Other challenges faced by survivors

Physical health issues and mental health issues are discussed in Chapter 3. Other common problems and support for coping with these challenges are discussed here.

1. Spiritual concerns -Personal reflection of a cancer survivor

- Many cancer survivors worry thinking about why he/she had cancer.
- Some think of reasons for surviving from cancer while some think of reasons for dying of cancer.
- They tend to re-evaluate their beliefs in life while recalling their cancer experience. Therefore, they consider cancer experience as a “wake-up call”.
- Some may tend to re-evaluate their priorities such as their role in the family, their job satisfaction, etc.
- Some may reach out for spiritual support.
- Some may find new solutions to improve their psychological well-being.

2. Social issues

Some cancer survivors experience issues related to marriage, work /school related, stigma, etc.

- Every survivor’s situation is different.
- Many survivors return to their day-to-day life (work/school) after treatment.
- Some may have worked throughout the treatment.
- Some may not be able to work due to long-lasting side effects or disability.

3. Financial issues

- Reasonable knowledge on financial management is very important. Although a survivor goes back to work, his/her earning capacity may not remain the same as earlier.
- Possibility of alternative source of income could be considered.
- Understanding the difference between needs and wants is important.
- If there are considerable income losses and the patient’s earning capacity is considerably decreased, patient should be directed to take assistance from the social services department or other NGOs.

4. Fear of recurrence

- This is one of the most common concerns a cancer survivor can have. Therefore, it is important to adhere to the follow-up cancer-specific guidelines of the cancer survivor.

Support for coping with challenges

Getting support

- It may be either from government, non-governmental or private organizations. In the government sector the social services department is the main organization. In addition to the social service officer attached to each Divisional Secretariat, Grama Niladari and other relevant officers also provide support. In the private sector, NGOs and INGOs may help patients.
- Any form of support allows the patient to talk about his/her feelings and achieves coping skills. It has been revealed by studies, majority of people who take part in support groups have shown better quality of life, more appetite and better sleep.
- It has been identified that support groups can be a powerful tool for both patients and families. Talking with others in support groups can help ease loneliness and sharing of same experiences might help the patient to understand realities.

Types of support

There are various support programmes in different formats, such as one-to-one counselling, group counselling, support groups, etc.

Counselling

It is important to find a counsellor who has had some training and experience in taking care of people with cancer. The oncology team is the best way to get the suggestions on counsellors in the area.

Support group

There are formal as well as informal support groups. Through the healthcare team, or through websites or publications, patients can find these groups.

Formal support groups focus on learning about cancer or dealing with feelings. Some groups are made up only of people with cancer or only of caregivers, while some include spouses, family members, or friends. Other groups focus on certain types of cancer or stages of the disease. The length of time these groups meet, can range from a set number of weeks to an ongoing programme.

In the Sri Lankan context, it is recommended to establish cancer survivor support groups guided by a health care worker at the institutional level /in the community.

Chapter Five

Survivorship Care for Selected Cancers

Breast Cancer

Breast cancer is the most common cancer among females in Sri Lanka. Among all newly diagnosed cancers, 26% is breast cancers (National Cancer Registry, 2020). With the improvement of the treatment facilities and early detection of cancer, the long-term survival of breast cancer patients is common in Sri Lanka.

There are five key areas to focus on a breast cancer survivor

- Surveillance for breast cancer recurrence
- Screening for second primary cancers
- Physical and psychosocial long-term effects of breast cancer and its treatment
- Health Promotion
- Care coordination

Follow-up

The oncology unit is responsible for developing a follow-up care plan, surveillance and screening of a treated breast cancer survivor.

- “The objective of follow-up is to detect salvageable disease recurrence, new cancers and manage treatment-related complications.
- It is recommended to carry out clinical review which includes clinical breast examination;
 - every 3 months for the first two years
 - every 6 months for the next 3 years
 - annually thereafter
- An annual mammogram for 5 years following completion of treatment is recommended for all patients.
- Bone mineral density should be assessed annually in all patients treated with ovarian suppression and/ or treated with aromatase inhibitors and not treated with bone resorptive agents.
- There is no evidence that routine blood investigations, chest radiographs or ultrasound scans during follow-up improves outcomes and it is strongly recommended against performing these investigations.

- Key Recommendations for follow-up of patients after completion of adjuvant treatment should comprise clinical review ;
 - every 3 months for first 2 years
 - every 6 months for next 3 years
 - annually thereafter for the next 5 years
- An annual mammogram should be performed for 5 years.”
(National Guidelines for the Management of Early and Locally Advanced Breast Cancer in Sri Lanka, 2021)
- Regular gynaecological assessment is needed for patients on Tamoxifen, for any evidence of endometrial hyperplasia.

Physical and psycho-social late and long-term effects specific to breast cancer and its treatment

- It is important to assess for patients’ body image concerns. If body image concerns are there, it is good to offer adaptive devices (wigs, breast prostheses, etc.).
- Lymphoedema, fatigue, pain, peripheral neuropathy and musculoskeletal effects are common long-term side effects.
- Issues related to sexual health, premature menopause and infertility should also be addressed. Survivors of childbearing age may need reproductive endocrinology care.
- When relevant, genetic counselling is also important.

Lip, Tongue and Mouth Cancer

This is the commonest cancer among male patients in Sri Lanka. Oral cancer is strongly associated with life style and environment risk factors and has a greater impact on the quality of life of the individual. If detected early, it’s curable, usually with some form of a surgery.

Follow up

Follow-up management plan for cancers of the oral cavity and the lip is given by the treating Oncology and Oral Maxillo-Facial (OMF) Surgical Unit.

“Follow-up recommendations are based on risk of relapse, second primaries, treatment sequelae and toxicities.

- History and physical examination
 - Year 1, every 1-3 months
 - Year 2, every 2-6 months
 - Year 3-5, every 4-8 months
 - After 5 years, annually

- Post- treatment baseline imaging of primary site
 - Recommended within 6 months of treatment as clinically indicated.
 - Further reimaging as indicated based on signs/symptoms; not routinely recommended for asymptomatic patients.
 - Chest imaging if clinically indicated.
- Assessment of treatment related hypothyroidism
 - TSH every 6-12 months if the neck has been irradiated
- Speech/hearing and swallowing evaluation and rehabilitation - as clinically indicated
- Smoking cessation and alcohol counselling - as clinically indicated
- Dental evaluation

(National Guideline for Management of Oral Cancer Sri Lanka, 2020)
- Body image concern, anxiety and stress
 - Regular screening for body image disturbances, distress, depression and anxiety with validated instruments (eg: NCCN Distress Thermometer or others) is recommended.

(American Cancer Society head and neck survivorship guideline)
- Screening for second primary detection
 - Lung cancer is more common.
 - Early assessment of oropharyngeal and oesophageal cancer is recommended.
- Health promotion
- Care co-ordination

Colorectal Cancer

Treatment for colorectal cancer includes surgery, chemotherapy, and radiation. These forms of treatment can cause short-term side effects as well as long lasting effects that impact your everyday life. Long-term follow-up care should include:

Follow up

Surveillance for colon or rectal cancer recurrence

The follow-up plan (given by the oncology unit) will differ from patient to patient. It usually includes the following:

- Physical examinations
- Colonoscopy
- Computed Tomography (CT) and other imaging
- Tumor markers

Preventing recurrences

Promoting a healthy lifestyle may help lower the risk for recurrence as well as the risk for developing other health conditions. It is important to follow the care plan recommendations on screening and follow-up visits.

Managing the side effects of treatment

- Colorectal cancer treatment can cause several physical side effects: temporary or long lasting.
- Common side effects are fatigue, bowel changes, urinary changes, difficulties with sexual health or intimacy, effects related to ileostomy /colostomy, emotional issues, etc.
- Primary care team should get assistance from supportive services and do the referrals to experts who can help with post-treatment issues in colorectal cancer survivors.

Paediatric Cancers

Childhood cancers can be described as cancers occurring up to 19 years of age. Around 1000 childhood cancer patients are newly detected per year in Sri Lanka. Over the past three decades, the survival of many childhood cancers has improved significantly due to the vast improvement in medical treatment and other supportive facilities.

The most commonly found childhood cancers in Sri Lanka are as follows.

- Leukaemias (male 51%, female 41%)
- Lymphomas (male 10%, females 7%)
- Central nervous system and brain tumours (males 9%, females 11%)
- Neuroblastoma and other peripheral nervous system tumours (male 2%, females 5%)
- Retinoblastoma (male 3%, females 4%)

(Childhood Cancer Registry Sri Lanka, 2020)

It is very challenging to complete the treatment of childhood cancer due to the child him/herself as well as due to the family. It also brings new challenges to the family and the child such as adjusting to new routines of life, etc. Furthermore, there are many fears and anxieties such as the fear of cancer recurrence and the fear of adjusting to new challenges of life.

Follow up

For every child, a survivorship care plan needs to be developed by the oncology team, considering;

- Type of cancer, stage, the treatment received and its response
- Practical issues to follow the treatment properly
- Future plan for the education, long-term health care, fertility issues, quality of life etc. (depending on the age)
- The possibility of providing health care resources for each patient
- The child must be regularly followed up to identify the;
 - Recurrence of cancer
 - Occurrence of second primary cancer
 - Damage to organs (eg: heart, lungs, liver, kidneys)
- Regular follow-up care of the child depends on the;
 - Type of cancer
 - Type of treatment
 - Genetic factors of the child
 - Other medical disorders of the child

Long-term effects of cancer

- Late effects of cancer and treatment may affect organs, tissues, and body function, growth and development, mood and feelings, thinking, learning, and memory. Social and psychological adjustment.
- Long-term effects of cancer can be physical including nutritional, emotional, and cognitive. It is important to get to know about the late effects on the child following cancer to plan the needs of the child.
- Most of the parents become anxious when they do not know the prognosis.

Cervical Cancer

Cervical cancer is the sixth commonest cancer among females in Sri Lanka. The incidence of cervical cancer increases with age and comes to a peak at the age of 60 – 65 years (National Cancer Registry, 2020). It is a preventable cancer through preventive vaccination and is curable when detected early by regular screening and providing effective treatment. The World Health Organization has declared a global strategy to accelerate the elimination of cervical cancer by achieving interim targets by 2030.

Follow up

Oncology unit is responsible for developing follow-up care plan for cervical cancer patients.

“The recommended surveillance is based on the patient’s risk for recurrence.

- Clinical history & examinations
 - In 3 months interval for 2 years
 - Then 4 – 6 months interval for 3 – 5 years
 - Then annual follow-up
- As the detection rate of recurrent cervical cancer is low using cervical and vaginal cytology alone, a good clinical evaluation is mandatory.
- For patients who have had fertility-sparing surgery, annual cervical or vaginal cytology tests can be considered as indicated for detection of lower genital tract dysplasia.
- MRI pelvis, 3 months after completing definitive treatment (only if available).
- Investigate with biopsy and imaging if patient becomes symptomatic.
- Hormone Replacement Therapy (HRT) is recommended with risk assessment for women who have lost ovarian function as a result of either surgery and/or radiotherapy for cervical cancer.”

(National Guidelines for the Management of Cervical Cancer in Sri Lanka, 2021)

Symptoms and signs to be looked at during survivorship, for evidence of cancer recurrence

- Abnormal vaginal bleeding
- Vaginal discharge
- New masses
- Pelvic or abdominal pain
- Bloating, Nausea, Vomiting
- Changes of bowel and urinary habits
- Loss of appetite
- Significant weight loss

Adverse side effects after treatment of cervical cancer

Side effects specific to cervical cancer such as post-surgical, post-chemotherapy and post-radiotherapy side effects are included in this chapter, while other common side effects are discussed in chapter 3.

Early menopause

- If oophorectomy is done during the surgery or following chemotherapy/ radiotherapy, sudden onset of early menopause can occur.
- Signs and symptoms of menopause are; hot flushes, night sweats, vaginal dryness, decreased libido, sleep disturbances, mood changes, cognitive changes, fatigue, osteoporosis, cardiovascular diseases cognitive dysfunction, etc.
- This may be very distressing for some survivors. Some pharmacological and non-pharmacological interventions are used to reduce many of these side effects.
eg: meditation, exercise, weight loss, relaxation techniques, etc.
- It is understandable to have concerns regarding sexuality following surgery.
- For vaginal dryness vaginal moisturizers and lubricants can be used.
- For young survivors systemic or vaginal oestrogen therapy can be recommended.
- For insomnia, may need psychiatry referral for further management.

Side effects following chemotherapy

- Fatigue, lymphoedema (Leg swelling), peripheral neuropathy, and cognitive dysfunction are common side effects among cervical cancer patients following chemotherapy.

Side effects following radiation therapy

- The commonest side effects following brachytherapy and radiation therapy are vaginal tightness and scarring.
- This can cause sexual intercourse very painful and vaginal dilators can be useful for it.
- Other common side effects are; dryness and fistula formation, bladder dysfunction, bowel dysfunction, etc.

Adverse effects on mental health and quality of life

It is normal to feel distressed, anxious, and sad after being diagnosed with cancer. Those feelings may subside with time, but if the survivors find that those feelings are interfering with enjoying their life, an opinion of a psychiatrist must be obtained.

Maintaining a healthy lifestyle

Maintaining a healthy lifestyle is important to improve quality of life, reduced cancer recurrence, and increased life span.

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