

A Guide for Teenagers and Young Adults with Cancer

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Introduction and Acknowledgements

I designed this booklet with the aim of helping teenagers and young adults who have received a cancer diagnosis. When I was 15 years old, I was diagnosed with Hodgkin's lymphoma and treated in a children's hospital. I found that there was a lack of written educational materials available for teenagers and young adults at the time. A cancer diagnosis can be a lonely and worrying time. This booklet is based on my personal experience and insights of cancer and is designed to support teenagers and young adults who may be going through similar circumstances.

Thanks to the Health Service Executive and Galway Children & Young People's Services Committees for helping me with this project.





People experience a range of feelings following a cancer diagnosis. It may take some time to process how you are feeling. Psychological support is available for those who require it. There is often a psychologist on the cancer care team. You may wish to discuss your feelings and concerns with a medical professional or trusted individual.

You may be going through bodily or hormonal changes and it may be difficult to acknowledge your feelings or accept new changes to your physical appearance. It may be helpful to write down how you feel and what positive actions may help you to feel better.

I felt that talking to nurses and other healthcare professionals about any concerns I had was helpful. Express your feelings. Sometimes, having a good cry is exactly what the doctor ordered.





Feelings

A cancer diagnosis comes as a shock to the patient and their family. You may have to make some lifestyle changes in order to accommodate hospital appointments and to reduce your risk of acquiring an infection. You may not have the freedom to live as before. Some days are going to be harder than others. It is normal to feel worried, confused or uncertain.

You may feel lonely or sad at times and may feel like 'nobody understands me' or 'I am different to other people'. Each person's cancer journey is different. Healthcare professionals will do the best they can to ensure you are feeling ok. You may wish to seek counselling during or after cancer treatment.





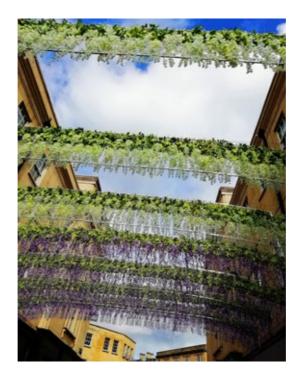
Below is a list of things I can do to make me feel better whenever I am feeling sad.

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Treatment

There are several treatment options for someone who has received a cancer diagnosis, including chemotherapy, radiotherapy or surgery. The type and duration of treatment depends on the age of the patient, type of cancer and stage of disease.

Treatment options are discussed in detail with the patient before treatment begins. The patient must sign a consent form to confirm that they have read and understand the information regarding their cancer treatment. A parent must consent to their child receiving cancer treatment.



Treatment

A lot of time is spent in hospital when a person is being treated for cancer. You may spend weeks, months or over a year attending hospital appointments. You may have questions about your cancer, about your treatment, about your feelings or about life after treatment. It may be helpful to write down any questions you may have for your doctor.



Treatment

Depending on the type of cancer you have, you may be taking a lot of medication. Chemotherapy drugs may be administered in pill or capsule form or as an infusion into the vein. Cancer patients often experience a variety of side-effects, including weakening of bones or muscles, fatigue, decreased energy levels, nausea and vomiting, anemia and infections. Side-effects come and go and can range in severity. Some side-effects of cancer treatments are easily treated, while others are harder to manage. Side-effects may appear during or after cancer treatment. When I was being treated for cancer, I experienced many side-effects. Side-effects took a toll on me emotionally and physically and it was important for me to rest often.

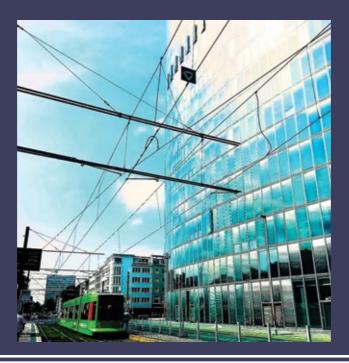


Daily Life

If you feel well enough, keep up your daily routine as much as possible. You may make some lifestyle changes if you are feeling tired. You may like to try out new hobbies.

It is good to keep the mind active and to do things that you enjoy. Although you have cancer, you can still have happiness and joy in your life. While I was receiving cancer treatment, I took up hobbies such as jewellery-making, cardmaking, painting, sudoku puzzles and making jigsaws. These kept my mind active and kept me busy without requiring a lot of energy.

Take some time to rest each day and limit the amount of time you spend on social media. You should ask family members for help if you are struggling with daily tasks.



Read a book/magazine/ study

Draw, colour

Listen to music

Play a musical instrument

Go for walks

Spend time outdoors (wrapped up warm!)

Experiment with makeup

C<mark>ook, bake, tr</mark>y new recipes

Jigsaws, word searches, crosswords, sudoku puzzles



Daily Life

Regular light activity recommended while receiving cancer treatment. Light activity includes regular walks and household chores. Strenuous exercise or activities should be avoided. You should discuss with your doctor what activities are safe to enjoy. You may enjoy creative activities such as art and music.

If you are working, you should discuss with your manager about taking time off. You should take off as much time as required and return to work when you are physically and emotionally prepared.







Body Image

Body image issues can affect everybody, regardless of age or gender.

Cancer treatments often cause many physical changes to your appearance. You may experience hair loss, decreased muscle tone or changes in weight.

Changes to body image can cause low self-esteem. Changes to your physical appearance may be particularly upsetting if you are a teenager or young adult who is still growing and physically maturing.



Body Image

You may like experimenting with makeup or may wish to wear a wig. There are lots of scarves, bandanas and hats available in a variety of styles for those who lose their hair.

It may take some time to adjust to changes in your physical appearance, so treat yourself with kindness. Learning to be comfortable with your body is a personal journey. Physical changes may be temporary or permanent. If your hair fell out as a result of cancer treatment, it will grow back soon.

You may like to discuss how you are feeling with a counsellor or healthcare professional.

Body Image

When my hair started falling out, it was a shock at first. Once most of it had fallen out, I had gotten used to the way I looked and began to be more comfortable in my own skin. I felt confident while in the hospital environment, however when I was in public, I sometimes felt self-conscious or embarrassed. People would often stare at me, including young children and adults. This affected my self-esteem. However, there were good days and bad days. I like make-up and was often complimented by nurses and family members about my make-up, long eyelashes or how the 'pixie cut' suited my face shape. Experimenting with make-up and trying out different hats and bandanas helped to boost my self-esteem. Becoming comfortable with how I looked took a while. As time went on, I worried less about my physical appearance as the focus was more on restoring my health.



Diet

Many studies suggest that certain foods called 'superfoods' are good for us. A healthy, balanced diet will provide you with the nutrients you require. Reading food labels carefully can help you to make healthy food choices. A healthy, balanced diet is good for your overall emotional and physical wellbeing. Healthy food can increase your energy levels. It may be helpful to keep a food diary to keep track of the foods you eat. You should aim to eat a diet that is rich in fruit and vegetables, while keeping sweet treats to a minimum.



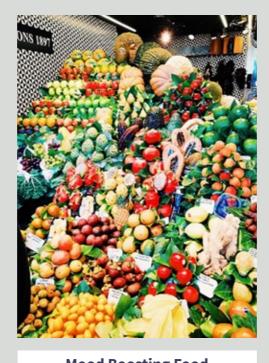




Diet

Do not make any sudden changes to your diet, unless recommended to do so by a healthcare professional. Some cancer treatments may reduce your appetite. If you would like to make changes to your diet, you may wish to discuss this with a dietician. There is often a dietician on the cancer care team to answer dietary-related questions and provide support. When I was receiving cancer treatment, a dietician discussed my diet with me and answered any questions that I had.

Diet







Exercise

Physical exercise helps reduce the risk of developing cancer and other diseases. An active lifestyle is good for your mood. The physical activities you can enjoy while receiving cancer treatment depends on your age, the type of treatment you are receiving and your fitness levels.

It is recommended to do light exercise while receiving cancer treatment. Household chores such as dusting or mowing the lawn are ways of keeping active without being too strenuous. Take things easy and don't push yourself to do too much. I enjoyed going for walks and I regularly helped with housework, when I could.



Exercise

Cancer treatments often cause decreases in energy levels, as well as bone and muscle mass. Your ability to do physical activity or strenuous exercise is often reduced as a result. People often regain their fitness levels and stamina following cancer treatment. However, it can take time to rebuild your physical strength and capabilities, so you must have patience.

You may have been part of a sports team and feel disheartened or angry. It is normal to be upset. You may wish to discuss how you feel with a healthcare professional or a member of your sports club.



Relationships

The emotional support of family and friends during this time is important for your wellbeing. Many relationships become stronger following a cancer diagnosis.

Patients going through cancer treatment are often at a high risk of infection. You may not see your friends and family as often while undergoing cancer treatment. This can be difficult at times. There are many ways of keeping in touch with family members, such as social media, sending an email or writing a letter.

Keeping in regular contact with family members helped me to maintain a positive attitude throughout my treatment.

Relationships

A cancer experience is different for every person. Talking to others who have been through a similar journey may be helpful.

Organisations such as Barretstown and Canteen Ireland allow young people who have or have had cancer to come together and share their experiences, while having fun. Events and activities are organised for patients and their families.

The patient and their family may make friends with other patients and their families while attending hospital visits. People with cancer and their families understand what other families in the same situation are going through. Connecting with others is important.







Back to Reality

Energy levels will return to normal eventually. You should rest often as your body recovers. Practicing meditation or yoga might be beneficial to help restore the body's energy and muscle tone.

I felt that regular light activity such as going for walks and spending time outdoors helped to clear my mind and regain my physical strength following cancer treatment.

Cancer is undoubtedly a life-changing experience. You may decide to make lifestyle changes following cancer treatment.



Back to Reality

It may take some time to return to 'normal'.

You may have missed out on a lot of school or college and you may feel left out or behind with work. It may be good to return to work or school one or two days a week at a time, until you feel ready to return fulltime.

You may tell people about your cancer experience or may prefer not to tell anyone. You do not have to disclose information that you do not feel comfortable sharing.

I found that people were very supportive when I returned to school. Teachers and classmates welcomed me back and were very helpful and caring.



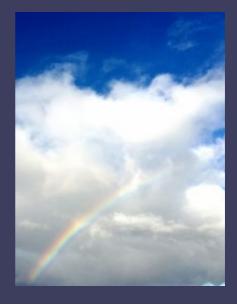


Looking Forward

Establish healthy relationships with those around you and surround yourself with people you feel comfortable with. Positive social interactions are uplifting and have a good impact on your attitude and emotional wellbeing.

Set short-term realistic goals for your future. Do things that you enjoy and what makes you happy.

Nobody knows what the future holds. There is always support whenever you need it and you are never alone.









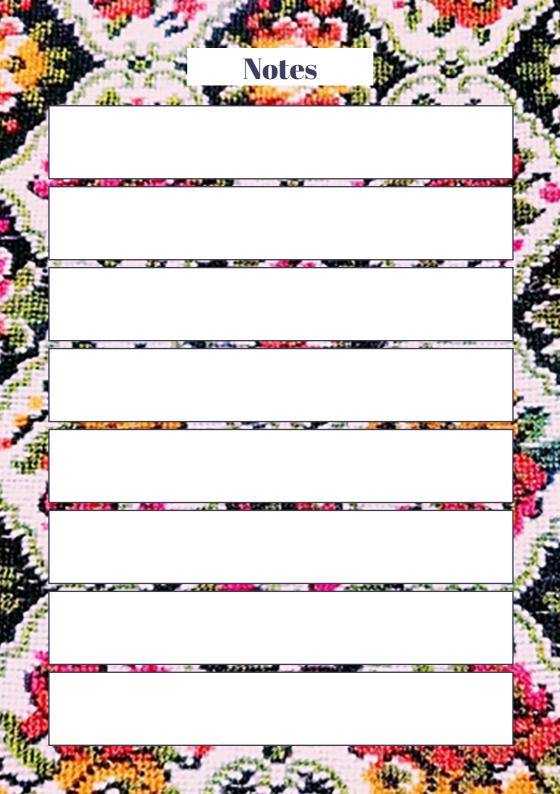
Looking Forward

Everybody's personal experience with cancer is different.

Look forward to the future. Think of your ambitions, life goals, career aspirations and places you would like to go.

I feel that my cancer experience has made me a more optimistic and strongminded person.





Support Services

Freephone Support Line

Childline	1800 666 666
Irish Cancer Society Cancer Nurse	1800 200 700
Samaritans	116 123
Text 'Hello'	50808

Websites

www.barretstown.org www.cancer.ie www.cancercarewest.ie www.canteen.ie www.mentalhealthireland.ie www.spunout.ie www.tusla.ie www.yourmentalhealth.ie www.youthworkireland.ie

My local GP

(phone)





