



The Clatterbridge  
Cancer Centre  
NHS Foundation Trust



# The Regional Late Effects Service

General information

**A guide for patients and carers**

# Contents

Clinic and appointment.....	1
Purpose .....	1
Clatterbridge Cancer Centre Late Effects Clinic Non-Attendance Policy.....	2
Treatment .....	3
Worries and concerns .....	4
Lifestyle choices .....	4
Staffing.....	5

This information booklet is for patients who have been referred to the Late Effects Service.

You have been referred to the Regional Late Effects Service by our colleagues in children’s or Teenage and Young Adult (TYA) services as you have reached an age where your care is going to be transferred over to adult services. We often refer to this time as the transition between children’s and adult services. We would like to continue to offer you regular follow up in order to identify, assess and treat any problems which may arise. Any medical, psychological or social issues you may have as the long term effects of your cancer and or its treatment are referred to as the “late effects”.



## Clinic and appointment

You have been referred to the Regional Late Effects Service which is held at the Clatterbridge Cancer Centre, Liverpool (which is on the University Hospital Aintree site). We would like to welcome you to the team and have put together this leaflet to tell you about some of the services we have available.

With this leaflet you will have also been sent an appointment for your initial clinic appointment. If this appointment is not at a convenient time please contact the team and we will be pleased to rearrange this with you.

## Purpose

This service is provided for adult survivors of childhood cancer and other tumours. Its purpose is to ensure that any issues arising from the diagnosis or its treatments are dealt with.

- It is also an opportunity for you to learn more about the treatment you had as a child/ young person and any long term problems or risks that might be associated with this.
- The clinic will help to coordinate any medical investigations or assessments you may need.
- We are also aware that an encounter with cancer can raise concerns and it is important to be able to discuss these and have them addressed.

- The clinic will also provide you with information about healthy lifestyle choices in order that you are empowered to make informed choices about your future health and wellbeing.
- Where appropriate, a telephone follow up clinic appointment may also be offered

## Clatterbridge Cancer Centre Late Effects Clinic Non-Attendance Policy

We understand that it is not always possible to attend your hospital appointment. If the time and date allocated to you is inconvenient, please contact the clinic clerk on **0151 556 5389** who will be happy to rearrange your appointment. This will allow us to use this slot for another patient. To enable as many patients as possible to access the Late Effects Clinic we have the following policy in managing unfilled appointments when we have not been contacted by the patient:

**First 2 missed appointments** – We understand that mistakes happen and it's easy to forget or mislay your appointment. Therefore we will resend an appointment for around 6 months depending on available slots.

**3rd missed appointment** – We will not allocate any further appointments routinely but we would still be pleased to see you in clinic at yours, your carer's or your GP's request. Please contact the clinic clerk on **0151 556 5389** to arrange an appointment in the Late Effects Clinic.



## Treatment

Some of the treatments for childhood cancers can increase your risk of secondary health problems. If the treatment you received has increased your risk you are likely to be receiving regular medical reviews and assessments. Possible risks are:

**Heart problems** - Some of the drugs used as treatments are associated with changes to the heart muscles, and for people where this risk is identified you will be referred for regular cardiac review. In addition to this the clinician who sees you in your appointment will discuss with you lifestyle changes which will help you to protect your heart. These include avoidance of smoking, maintaining a sensible weight, eating a healthy diet, taking alcohol in moderation and participating in regular exercise.

**Bone health** - Some people will have been given steroids as part of their treatment, and in childhood steroids can prevent the laying down of strong bones. If you did receive steroids as part of your treatment we may ask you about any fractures you have had. For those people who are felt to have an increased risk of changes to their bones it is recommended to have adequate vitamin D and calcium intake as you continue to build up your bone strength into your 20's. Regular exercise can also help to improve bone strength (have removed this to avoid confusion as it is high impact sports that help bones, unless they are damaged).

**Fertility** - For women, chemotherapy in child or early adulthood can damage some of the eggs in the ovaries. This can sometimes affect a woman's ability to conceive. In some cases there may be

an increased risk of early menopause. The risks of these are quite small but more information and access to support and specialist advice can be sought through the late effects clinic.

For men the treatment can affect your sperm count and in some cases has left men with fertility issues. Again, advice and specialist services can be accessed through the late effects clinic.

**Second malignancy** - Unfortunately anyone who has been treated for a cancer in childhood has a slightly higher risk of getting a secondary cancer than in people of the same age range. This is due to genetic risk and as the result of the treatments (especially radiotherapy) you have had affecting healthy cells. This risk is usually very small but this will be discussed with you and is another reason why lifestyle and healthy living options are promoted.

## Worries and concerns

After a diagnosis of cancer we are aware that many people have worries and concerns about their health. It is normal to have these and we would encourage you to voice these at your appointment.

## Lifestyle choices

In order to maintain excellent health for a good quality of life, it is important for our patients attending the Late Effects Clinic to avoid additional avoidable health risks. We will discuss and advise on lifestyle choices such as smoking, alcohol intake, diet and exercise.



The Late Effects Clinic is held on the 2nd and 4th Wednesday of the month at Clatterbridge cancer Centre, Liverpool (University Hospital Aintree site). For some patients who do not require face to face contact with the team we are now offering telephone clinics which are run by our Clinical Nurse Specialist. These clinics are not suitable for everyone, but where it is felt appropriate you may be offered this as an option. If you would prefer to have a face to face appointment you can request this instead.

## Staffing

When attending the Late Effects Clinic for standard appointments you will be seen by either a member of the medical team or a Clinical Nurse Specialist. During your initial appointment they will discuss with you your treatment, any issues or concerns you may have. This information will be set out for you in your treatment summary and you can request a summary of this at any time.

The Late Effects team is not only for the follow up of your medical condition but offers practical help and support to manage other issues your cancer may cause. The team also has input from a number of other professionals who can organise to meet with you or to help coordinate referrals to your local services.

### **These include:-**

Clinical Psychologist	Oncology Social Worker
Macmillan Benefits Advisor	Endocrinologist (Hormone Specialist)
Cardiologist (Heart Specialist)	Fertility Specialist

## How we produce our information

All of our leaflets are produced by staff at The Clatterbridge Cancer Centre and this information is not sponsored or influenced in any way. Every effort is made to ensure that the information included in this leaflet is accurate and complete and we hope that it will add to any professional advice you have had. All our leaflets are evidence based where appropriate and they are regularly reviewed and updated. If you are concerned about your health in any way, you should consult your healthcare team.

We rely on a number of sources to gather evidence for our information. All of our information is in line with accepted national or international guidelines where possible. Where no guidelines exist, we rely on other reliable sources such as systematic reviews, published clinical trials data or a consensus review of experts. We also use medical textbooks, journals and government publications.

References for this leaflet can be obtained by telephoning 0151 556 5570.

If you need this leaflet in large print, Braille, audio or different language, please call 0151 556 5570.

**If you have a comment, concern, compliment or complaint, please call 0151 556 5203.**

The Clatterbridge Cancer Centre NHS Foundation Trust  
Clatterbridge Road, Bebington,  
Wirral, CH63 4JY.

Tel: 0151 556 5000

Web: [www.clatterbridgecc.nhs.uk](http://www.clatterbridgecc.nhs.uk)

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