

The ROYAL MARSDEN

NHS Foundation Trust

Empower Pathway: Testicular cancer follow up

Your guide to remote monitoring and personalised care

Empower Team

Patient Information



NHS

Contents

Introduction	1
The Empower Team	1
Symptoms that may be associated with relapse	1
Testicular cancer overview	2
Remote monitoring and personalised care	2
What is the Empower Pathway?	3
How long does the Empower Pathway last?	4
Follow up investigations	5
Tumour markers	5
Chest x-ray	6
Computerised Tomography (CT) scan	6
Magnetic Resonance Imaging (MRI) scan	6
Testicular self-examination	7
Your Key worker	7
Other symptoms and concerns	7
Living well after your treatment	11
Contact details	14
Further information and support	14

Introduction

This booklet introduces the Empower Pathway for people who have been treated for testicular cancer at The Royal Marsden.

Follow up after treatment for cancer is necessary as a small number of people can relapse. It is also an important time to identify and treat any problems which you may have after your treatment.

This booklet contains:

- A summary of remote monitoring and supported self-management
- Details about your follow up investigations
- Wellbeing information and support
- Contact details for the testicular cancer team if you have any concerns.

The Empower Team

We work together to support you on the pathway. The team includes an:

- Advanced Nurse Practitioner
- GP with an interest in Testicular Cancer
- Pathway Co-ordinator.

Symptoms that may be associated with relapse

If you experience one or more of the following symptoms persistently without improvement, you should contact us:

- Unexplained weight loss
- Concerning pain – abdominal (tummy), back, or testicular
- Unexplainable shortness of breath
- Testicular swelling
- Cough (in isolation, for more than 4 weeks).

We will discuss your symptoms with you and, if necessary, will arrange to see you as soon as possible.

Testicular cancer overview

There are two main types of testicular cancer: seminoma and non-seminoma. These are sometimes referred to as germ cell cancers. They occur most frequently between the ages of 15–50 years old. Rarely, germ cell cancers can start in the chest, or abdomen (tummy), without involvement of the testicles.

Initial treatment for testicular cancer may involve:

- An operation to remove the affected testicle (orchidectomy)
- An operation to remove cancer cells at other sites
- Chemotherapy (drug treatment)
- Radiotherapy (x-ray treatment)
- Or a combination of these.

Remote monitoring and personalised care

Although most patients with testicular cancer will be cured by their initial treatment, for some, the cancer will recur. If this happens, you will require more treatment. The purpose of follow up is to detect any recurrence of testicular cancer at an early stage, so it can be treated as quickly as possible. It is also an opportunity to identify and support with any after effects of treatment.

In the past, patients living with, or after testicular cancer have been seen at regular intervals by their consultant clinical team. Some patients find these pre-arranged, face to face appointments useful and reassuring, however others find them a source of anxiety and not particularly helpful, unless they have something specific they wish to discuss. Surveillance tests are important to monitor for signs of recurrence. These appointments can be either face to face at the hospital or virtually, via video or text using MyMarsden.

We can address your symptoms and concerns more quickly if you report them as and when they occur, rather than waiting for a routine appointment. Please do not hesitate to contact us if you have any concerns.

We have introduced a different way of managing follow up care, called the Empower Pathway.

What is the Empower Pathway?

Instead of having one size fits all appointment, the Empower Pathway will comprise of two main areas.

Personalised care and supported self-management: This puts you in control of your care and allows you to take an active and leading role in your recovery, along with support from your specialist testicular cancer team.

During your treatment and care, a member of your team will discuss supported self-management with you. We will discuss your physical, mental, and social health alongside your cancer follow up. Together, we will come up with a personal care plan. This will help you take control of your health and care.

You will also have access to the Empower video seminar pack.

Your surveillance plan is the term used to describe the tests (investigations) that we will arrange for you when you start on the Empower Pathway. These are the same tests that you would have if you remained within the Consultant led clinic. A recurrence of your testicular cancer is likely to be detected by one or more of the following investigations:

- Blood tests (measuring serum marker levels)
- Chest x-ray
- Computerised tomography (CT) scan
- Magnetic Resonance Imaging (MRI) scan.

See page 6 for more information on these tests. During your follow up period, you will need to have one or more of these investigations at regular intervals. We will give you a schedule for these tests and provide the test results as soon as possible.

The Empower and Consultant teams work very closely with one another. During your time on the Empower Pathway, if there is any sign of recurrence, you will be seen back in a Consultant led clinic.

You will only need to attend the outpatient clinic (at hospital) for your scheduled surveillance tests or for the following reasons:

- If your test results are abnormal
- If you have a problem or concern that you wish to discuss
- If this is identified as part of your personalised plan
- If you wish to be seen face to face
- When we discharge you from the Empower Pathway at the end of your follow up period.

At all other times, we aim to communicate your results to you via telephone or virtually (text or video consultation are both available through MyMarsden), whichever you prefer.

How long does the Empower Pathway last?

All people who receive treatment for testicular cancer will require follow up. This will usually be for five years after finishing treatment although some patients will continue with follow up appointments up to 10 years or indefinitely.

After your follow up period, your GP will become your main point of contact for any concerns. One of the aims of this pathway is to make this transition as smooth as possible.

If you change your contact details or GP whilst on the pathway, please notify the Empower Team.

Follow up investigations

It is important that you have these tests done at the intervals set out in your personal schedule.

Your Empower Team will arrange your blood tests, chest x-rays and scans in line with your follow up schedule.

- Blood tests and chest x-rays should be performed as close to the scheduled date as possible
- CT and MRI scans are booked appointments. If you cannot make the scheduled date, please let us know so the appointment can be given to someone else. If necessary, we can always reschedule an appointment to a more convenient time.

The testicular cancer team will send you a letter within one month of the tests being completed to let you know the results. This may be done by text if you've registered for this service. If a test indicates that further investigation is required, we will contact you by telephone or text to discuss any actions.

The tests and scans we may ask you to have as part of your routine follow up include:

Tumour markers

Tumour markers can show us whether there is active testicular cancer or not. They are proteins that are normally present in small amounts in the blood, but can be produced by testicular cancers, resulting in higher levels. If your tumour marker levels are high, it may suggest that you have active cancer and will require further treatment.

Not all testicular cancers produce raised markers so some patients can have active cancer with normal tumour marker levels.

The tumour markers we are looking for are:

- HCG (human chorionic gonadotrophin): This can be raised in both seminoma and non-seminoma tumours
- AFP (alpha fetoprotein): This can be raised in patients with non-seminoma tumours
- LDH (lactate dehydrogenase): This can be raised in both seminoma and non-seminoma tumours.

Chest x-ray

Testicular cancer can spread to the chest, and a chest x-ray is a simple test that can help to detect this. Using a very low dose of radiation, a picture is taken of your chest and is examined to look for any abnormalities.

We keep the number of chest x-rays to a minimum so that you are not exposed to too much radiation.

Computerised Tomography (CT) scan

A CT scan is another type of x-ray that helps us to see what is happening inside your body. The pictures produced from the scan show more details than a normal x-ray (such as a chest x-ray), but they do expose you to higher levels of radiation. A CT scan is the same as having hundreds of x-rays at the same time. For this reason, we will only scan the area of your body where we think you have the most risk of having a recurrence of testicular cancer. We will also keep the number of scans performed to the minimum required.

Magnetic Resonance Imaging (MRI) scan

An MRI scanner uses a magnetic field and radio waves to build detailed pictures of various parts of the body by picking up signals sent by water molecules. These pictures are used to make diagnoses and to assess the effects of treatment. MRI scans are sometimes used for monitoring after testicular cancer.

Testicular self-examination

People who have had testicular cancer have an increased risk of developing a new cancer in the other testicle. It is therefore important to check your remaining testicle on a regular basis. If you feel a new lump or notice any change in size or texture, you should contact the testicular cancer team as soon as possible. They can arrange for further investigations if necessary.

Macmillan Cancer Support has more information on how to self-examine. Testicular cancer and self-checking [PDF, 4.34MB] [www.macmillan.org.uk/documents/cancerinfo/easyreadpdfs/testicularcancerandself-checking\[pdf,434mb\].pdf](http://www.macmillan.org.uk/documents/cancerinfo/easyreadpdfs/testicularcancerandself-checking[pdf,434mb].pdf)

Your Key worker

Your Key worker is a member of the Empower Team and will be your first point of contact for any queries.

Other symptoms and concerns

Sex and psychosexual concerns.

Removal of one testicle should not affect sexual function. Usually, the healthy testicle that is left will produce more testosterone and sperm to make up for the testicle that has been removed. However, sexual problems do sometimes occur in people with testicular cancer. In most cases they result from the emotional reaction to the experience of being diagnosed and treated for cancer. These problems can often resolve if you can discuss them openly. Whatever your relationship status, it can help to talk about the things that are worrying you. You may have a trusted friend or prefer to talk to one of our psychosexual therapists.

Sex with Cancer has more information and support. www.sexwithcancer.com

Occasionally sexual problems may occur because of treatment or because the remaining testicle is not producing adequate testosterone. If you have ongoing problems, it is important to let us know. We can then assess these to determine whether the cause is likely to be physical or emotional. If appropriate, we can refer you to a psychosexual therapist or endocrinologist (a hormone doctor).

Having children after treatment

Most people who have been treated for testicular cancer can go on to have children when they have recovered. There is no evidence that cancer treatment can harm children conceived after treatment is over. However, we recommend that you wait for at least one year after completing chemotherapy or radiotherapy treatment before trying to conceive. This gives the sperm time to recover from any damage that treatment may have caused. It is important to carry on using contraception throughout this one-year period.

Infertility may occur if your testicle is producing less sperm than normal or if the sperm produced are abnormal. This may happen because the remaining testicle has always been abnormal, or because it has been damaged due to the chemotherapy or radiotherapy treatment. Infertility caused by chemotherapy is usually temporary. The rate at which the sperm count recovers varies from person to person.

As there is a small risk of permanent infertility, all patients are offered the opportunity of sperm banking before starting treatment. Please note that this is not possible for those needing treatment as an emergency.

Sometimes successful treatment with chemotherapy improves sperm production in those with a low sperm count at the time of diagnosis.

If you think you may be experiencing any of these problems, please contact us. We may need to see you in clinic to assess this more fully.

The remaining testicle not working properly

Most people will have no problems with the remaining testicle after diagnosis, but sometimes it does not work as well as it should. When the testicle produces less testosterone than normal this is known as hypogonadism. This can cause a combination of any of the following symptoms:

- Loss of interest in sex
- Inability to have an erection
- Inability to keep an erection during sex or intimacy
- Difficulty with arousal
- Unexplained tiredness
- Mood changes
- Hot flushes/sweats
- Unexplained weight gain
- Development of breasts
- Decreased facial and body hair
- Tender nipples.

Testosterone levels can be measured by a blood test and testosterone replacement can be given to correct testosterone deficiency. If you think you may be experiencing any of these problems, please contact us or your GP.

Long-term side effects and late effects of treatment

Most people with testicular cancer will be cured by removal of the affected testicle, but some will require additional treatment with radiotherapy or chemotherapy. Some people with non-seminoma that has spread beyond their testicle will also require further surgery to remove remaining masses.

Some side effects that develop during treatment may take a long time to improve or may occasionally become permanent (long-term side effects). Other effects can develop many years after treatment has finished (late effects).

You may not experience any side effects at all. If you do have side effects, they may range from mild to serious.

Long-term side effects of chemotherapy can include:

- Changes in the feeling (sensation) in your hands or feet (peripheral neuropathy)
- Very cold hands that can look pale
- Hearing changes (particularly for high-pitched sounds)
- Lung problems
- Infertility.

These changes are usually temporary but may take up to 12 months to resolve. Occasionally they are permanent.

Late effects of chemotherapy can include:

- Gaining weight
- Raised blood pressure
- Raised cholesterol
- Diabetes
- An increased risk of heart disease
- Hearing issues.

It is important to let us know if you have symptoms that could be linked with treatment effects. If you have any of these issues in the future, please let your GP know. Further information is available via Macmillan Cancer Support Testicular cancer treatment late effects

www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/testicular-cancer-treatment-late-effects

Living well after your treatment

It is important to follow a healthy lifestyle after your treatment to help your recovery. Regular exercise, eating healthily, watching your weight and stopping smoking are important ways you can help yourself. NHS Live Well has more information and support www.nhs.uk/livewell/pages/topics.aspx.

Stopping smoking

Stopping smoking is one of the most important things you can do to keep yourself well. We realise this can be a difficult thing to do, but help is available. Please page 14 for useful contacts or ask the Empower Team.

Healthy eating

Everyone should try to eat a healthy, balanced diet but it is especially important when you are recovering from cancer.

Advice for a healthy diet:

- Eat the right amount to keep a healthy weight
- Eat plenty of fresh fruit and vegetables and foods with fibre and starch – these should form the main part of your diet
- Eat small amounts of fatty food (fast food, fried food) and small amounts of sugary food (such as cakes, biscuits and fizzy drinks). These should form only a small part of your diet
- Drink alcohol in moderation.

In the long-term, a healthy diet may reduce the chances of heart disease and diabetes, as well as certain types of cancer. If you find eating a balanced diet difficult after your treatment, please let the Empower Team know.

Physical activity

It is important to try and build exercise into your life after you have completed your cancer treatment. Regular physical activity of 30 minutes at least five times a week has been shown to help prevent and manage over 20 chronic conditions, including cancer.

HIIT classes (high intensity interval training) have been shown to be especially beneficial for people who have had testicular cancer. Strength and flexibility exercises will help you increase strength, maintain bone density, improve balance, and reduce joint pain.

We recommend that you try to gradually build up your daily activity, so that you can do at least three 20-minute sessions of moderate activity each week. Walking daily and gradually increasing the distance you walk is a good starting point. See page 14 for local contacts and NHS resources that can help you to become more active. The NHS website also has a range of fitness videos which you can try from home.

Fitness Studio exercise videos – NHS

www.nhs.uk/conditions/nhs-fitness-studio/

Mental health

We recognise that mental health issues can arise at any point, from your diagnosis to years after treatment. This may or not be related to your cancer diagnosis or care here at The Royal Marsden. As part of the Empower Pathway, we want to address any issues you may be having, as this can have ripple effects on your wider health.

If related to your diagnosis or care at The Royal Marsden, we can refer you for counselling or you can access help through the Maggie's Centre. Please see page 15 for further details.

If unrelated to your cancer diagnosis or care, there is always help available. Your local GP can refer you or signpost you to appropriate services. If you are struggling, then please get in touch with the Empower Team and we can help you to access local services.

The following links can signpost you to help in your local area:

NHS talking therapies NHS talking therapies – NHS

www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/

Self-help for generalised anxiety disorder Self-help – Generalised anxiety disorder in adults – NHS

www.nhs.uk/mental-health/conditions/generalised-anxiety-disorder/self-help/

Urgent mental health helpline Mental Health Helpline for Urgent Help – NHS

www.nhs.uk/service-search/mental-health/find-an-urgent-mental-health-helpline

If you feel this is an emergency, please contact 999 or attend your local Accident and Emergency.

Returning to work or education

If you are returning to work or college, it may help to have a meeting first with your employer, course tutor, human resources department or occupational health team. It can be useful to take someone with you to help take notes (such as a work colleague, students' union or student representative).

If you are still experiencing side effects from your treatment, you should discuss any reasonable changes that can be made, such as a phased return (in stages) or extra exam time.

Some useful questions to ask are:

- What adjustments could your employer arrange that would make work or college easier for you?
- Could you reduce your hours, work flexibly or work more at home?
- Can you have extended assignment times or extra exam time?
- What facilities are available if you need to rest at work or college during the day?
- Are there any counselling or student support services available?

Telling friends, other students and work colleagues about your cancer is the best way to overcome any uneasiness that they may have about what has happened to you.

They may be reluctant to bring up the subject, so take the lead and help them to help you. The Maggie's Centre can support you during this time. Please see page 15 for details.

Contact details

For all non-urgent enquiries to the Empower Team, please contact:

Tel 07435 629533
Email Empower@rmh.nhs.uk

An answerphone is available, and we will check messages on Tuesdays and Fridays. We will usually get back to you within two working days.

For any urgent or life-threatening issues, please call 999 or attend your local Accident and Emergency. If you have more urgent concerns specifically related to your testicular cancer, please contact The Royal Marsden Macmillan Hotline on 020 8915 6899.

Further information and support

In addition to your clinical team, there are several other organisations you may wish to contact who can help support you:

Local contacts

For a full list of all our support services, please see the Support services section of our website:

www.royalmarsden.nhs.uk/your-care/adult-support-services

The Royal Marsden Macmillan Hotline

This should be used for more urgent queries relating to recent treatment or care. They offer specialist advice and support to all patients. You can call 24/7 on 020 8915 6899.

Maggie's Centre

A charity which provides support for people affected by cancer. This includes psychological support and information on health, diet, exercise. There is a local Maggie's Centre based at The Royal Marsden, Sutton.

Website www.maggies.org

Tel 020 3982 3141

Email maggies.royalmarsden@maggies.org

National contacts

Citizen's Advice

Advice on finances including benefits, bills and council tax.

Website www.citizensadvice.org.uk

Cancer Research UK

Information about cancer types, diagnosis, prevention, clinical research trials and tools to help you cope with cancer.

Website www.cancerresearchuk.org

Tel 0808 800 4040 (to speak to a nurse)

Checkmads

An online community with a focus on testicular cancer awareness and support.

Website www.checkmads.com

NHS Live Well

Information and resources on health, diet, exercise and stopping smoking. It includes the popular and motivating Couch to 5K programme.

Website www.nhs.uk/livewell/pages/topics.aspx

NHS Fitness Studio

Over 20 instructor-led videos covering aerobic exercise, strength and resistance, Pilates and yoga.

Website www.nhs.uk/conditions/nhs-fitness-studio

Macmillan Cancer Support

Support for people with cancer as well as their loved ones. This includes information about cancer types, treatments and how to cope.

Website www.macmillan.org.uk

Tel 0808 808 0000

Orchid

Support and information for men affected by prostate, testicular and penile cancer.

Website www.orchid-cancer.org.uk

Tel 0808 802 0010

Sex with Cancer

Practical solutions, peer-led resources, and creative ways of connecting with your body and navigating your relationships with or after cancer.

Website www.sexwithcancer.com

Shine Cancer Support

Information and events for young adults diagnosed with cancer, including resources on dating, fertility and mental health.

Website www.shinecancersupport.org

Teenage Cancer Trust

An online community for 13–24 year olds diagnosed with cancer, and their friends and families. This includes resources such as an emotional support app and a social network for young people with cancer to connect.

Website www.teenagecancertrust.org

Trekstock

Practical and social support programmes tailored to the needs of young adults diagnosed with cancer. This includes events such as style nights to build your confidence after a cancer diagnosis.

Website *www.trekstock.com*

Turn2us

A charity offering financial support, including a benefits calculator and grants search.

Website *www.turn2us.org.uk*

Tel 0808 802 2000

Notes and questions

References

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

The Royal Marsden Help Centre

Telephone: Chelsea 020 7811 8438 / 020 7808 2083

Sutton 020 8661 3759 / 3951

Email: patientcentre@rmh.nhs.uk

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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