

# Your Diagnosis and Treatment Record

Insert Trust Name

This patient held record was developed by



Patient Name

NHS Number

## This is your patient held diagnosis and treatment record. This folder is an essential part of the communication between you and your medical team about your treatment for bladder cancer

The information provided, which will be updated as your treatment progresses, is an important part of how you and the Health Care team looking after you will record discussions about your care. This will enable us to ensure that you are informed about everything you need to know in a timely manner. We also hope this will make you feel more in control of your bladder cancer and follow up care.

### **This folder provides a written record of:**

- Your diagnosis and other clinical information
- Your Key worker, usually a Clinical Nurse Specialist (CNS) or other Health Care Professional (HCP), and other useful contacts
- The Multi-disciplinary team looking after you
- Support groups (local and national)
- Your Treatment pathway and care plan
- The information booklets you have been given
- A questionnaire to help us ensure that your health, other needs and practical requirements are discussed (called a Holistic Needs Assessment or HNA)
- A proposed follow up schedule for your treatment type
- Your check cystoscopy test results
- Symptom scoring sheets used for assessing any treatment side effects and the planned treatment to deal with these
- Clinical trials that are available to you with your particular type of bladder cancer.

# How you can help with your treatment

## Assessment tools

**Assessment tools** are questionnaires which you and/or your carer/supporter can complete if you wish to. They aim to assess your symptoms and help us discuss and plan appropriate care for you. The tools included in your record focus on common side effects of bladder cancer treatment.

You and, if you wish, your partner, families or carers will have the opportunity to have discussions at any stage during your treatment and care with:

- a range of specialist healthcare professionals, including those who can provide psychological support
- other people with bladder cancer who have had similar treatments.

**Your overall assessment and care plan will be individually tailored for you based on national and local treatment pathways for bladder cancer.**

## HNA (Holistic Needs Assessment)

The HNA aims to develop an understanding of what the person living with cancer and after treatment for cancer knows, understands and needs.

A holistic assessment is focused on the whole person. Your entire well-being is discussed – physical, emotional, spiritual, mental, social, and environmental. The HNA forms the basis of your individual care plan, in addition to your treatment pathway.

## Symptom questionnaires

Symptom questionnaires are used to identify any physical, sexual, practical, family, emotional or spiritual concerns you may have before starting treatment. They are also used after treatment to monitor your progress and any side effects related to your treatment. They also help with the discussion about treatment options. The symptom questionnaires used after your particular treatment are included within the relevant section of this record. These pages will be added to your record when your treatment plan has been agreed.

If you do not understand any of the terms used by the team looking after you or contained in this document ask your keyworker. You can also find this information on the websites for bladder cancer charities (page 6).

# How you can help with your treatment

## Your individual care plan

Once you have completed your holistic needs assessment, you will be asked to discuss this with your keyworker.

This will be used to help draw up your individual plan of care which is in addition to your treatment pathway.

## Your treatment pathway

There are national standards and treatment pathways for each and every cancer type and each pathway is adapted by healthcare providers to suit the needs of the local population. The healthcare team looking after you need as much information about your bladder cancer as possible so they can recommend the best treatment. This may mean that you have to have further tests before your treatment pathway is finalised. You can ask your clinical team for a copy of the treatment pathway for your type of bladder cancer. You can also refer to the NICE guidelines regarding treatment pathways <https://www.nice.org.uk/guidance/ng2/ifp/chapter/About-this-information>

In addition, you can find helpful information about bladder cancer when you have just been diagnosed here <http://fightbladdercancer.co.uk/get-help/just-diagnosed>

You and, if you wish, your partner, families or carers will have the opportunity to have discussions at any stage during your treatment and care with:

- a range of specialist healthcare professionals, including those who can provide psychological support
- other people with bladder cancer who have had similar treatments.

Your clinical team may have their own versions of the HNA, symptom questionnaires and HNA care plan (which you can keep in your folder along with this document). Standard versions of the HNA, care plan and assessment tools are also available in template form on the [British Association of Urological Nurses \(BAUN\) website](#).

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## Multi Disciplinary Team (MDT)

The multidisciplinary team consists of the team who ensure that you receive the best treatment, including any trials which may be suitable for you. The core members of the MDT include your keyworker, usually your Clinical Nurse Specialist (CNS), your consultant urologist and oncologist, however there will be many other people involved in your care.

**Key worker Name/Title:** \_\_\_\_\_

**Key worker contact details:** \_\_\_\_\_

**Key worker normal working hours:** \_\_\_\_\_

**Consultant Urologist:** \_\_\_\_\_

**Consultant Oncologist:** \_\_\_\_\_

**Secretary contact details:** \_\_\_\_\_

These key people are supported by other members of the multidisciplinary team. These other members of the Urology multidisciplinary team (MDT) include:

**Consultant Pathologist:** \_\_\_\_\_

**Consultant Radiologist:** \_\_\_\_\_

## Who to contact if you have concerns outside of your keyworkers working hours:

**Name of department:** \_\_\_\_\_

**Contact Number:** \_\_\_\_\_

# Bladder Cancer Support

Your nearest bladder cancer support group is:

**Contact details:** \_\_\_\_\_

**Meetings held:** \_\_\_\_\_

## Local Cancer Information Centre

**Based at:** \_\_\_\_\_

**Contact e-mail** \_\_\_\_\_

**Telephone** \_\_\_\_\_

## National Bladder Cancer Charities

**Action Bladder Cancer UK** have three main strands to their work:

- Improving outcomes for bladder cancer patients
- Improving research into bladder cancer
- Improving patient support

<http://actionbladdercanceruk.org>

**How to contact Action Bladder Cancer:**

Email: [info@actionbladdercanceruk.org](mailto:info@actionbladdercanceruk.org) Tel: 0300 302 0085

Please note that they are unable to advise on individual medical issues – please contact your medical team.

**Fight Bladder Cancer** is a patient and carer led charity set up to:

- Support people affected by bladder cancer
- Raise awareness about the causes of bladder cancer and its treatments so it can be caught early
- Campaign for (and support research into) this cancer
- Affect policy at the highest levels to bring about change in bladder cancer treatment

<http://fightbladdercancer.co.uk>

**How to contact Fight Bladder Cancer**

Email: [support@fightbladdercancer.co.uk](mailto:support@fightbladdercancer.co.uk) Tel: 01844 351621 between 9.00am and 5.00pm Monday to Friday. There is an answerphone for messages outside these hours or when they are very busy.

**The Urostomy Association** have been in existence for over 45 years, and have local Branches around the UK:

- They specialise in support for people with a urinary diversion and cover urostomy, continent diversions and neo-bladder/bladder reconstructions.
- They also offer support via a regular magazine, leaflets on a variety of topics, trained volunteers, closed Facebook group, website and telephone helpline.

Website: <https://urostomyassociation.org.uk/information/>

Telephone: 01889 563191. 8.30am to 5pm, Monday to Friday with answerphone at other times.

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## Written information I have been given:

Information Given (please list)	Date
<i>e.g. Smoking cessation</i>	

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## Bladder Cancer Staging and Grading

You need to know the stage, grade and risk category for your bladder cancer when you are diagnosed as this is how decisions are made as to what the best treatment for you is. The stage, grade and risk category may change over time and we will always tell you if there is a change.

Your consultant and keyworker will explain these terms to you. You can also find out more about these terms from the following resources:

Action Bladder Cancer <http://actionbladdercanceruk.org/types-of-bladder-cancer/>

Cancer Research UK <http://www.cancerresearchuk.org/about-cancer/type/bladder-cancer/>

Fight Bladder Cancer <http://fightbladdercancer.co.uk/learn/key-facts>

Macmillan Cancer Support <http://www.macmillan.org.uk/cancerinformation/cancertypes/bladder/bladdercancer.aspx>

A full list of the terms we use when talking about bladder cancer can be found here [http://fightbladdercancer.co.uk/sites/default/files/downloads/A\\_bladder\\_cancer\\_glossary.pdf](http://fightbladdercancer.co.uk/sites/default/files/downloads/A_bladder_cancer_glossary.pdf)

## My initial clinical summary at diagnosis

This table contains a lot of complex clinical information which is important in deciding what the best treatment pathway for you is. Not everything in this list will apply to you. your keyworker will tell you which tests are not applicable and why. If there is anything you do not understand, please ask your keyworker to explain it to you.

Date of biopsy/TURBT	
Bladder cancer type	
Grade	G _____
Stage	T _____
Size and number of tumours	
Photodynamic diagnosis/narrow-band imaging/Cytology /NMP22	Yes      No
Detrusor muscle included in histology	Yes      No
Immediate Post Operative MMC <input type="checkbox"/> Prescribed <input type="checkbox"/> Administered	Date: _____ Dose: _____ Time: _____ Signed: _____
<input type="checkbox"/> CT Date: _____ <input type="checkbox"/> MRI Date: _____	T _____ N _____
<input type="checkbox"/> Bonescan Date: _____ (if required)	M _____
Risk category	
Predicted risk of recurrence and progression using e.g. EORTC risk tables	
Local MDT discussion	Date: _____
Specialist MDT discussion (if required)	Date: _____

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## Clinical Trials for Bladder Cancer

You can ask your consultant if they know of any clinical trials that you may be eligible to join. Taking part in a clinical trial may not benefit you, but may help future patients by testing treatments to see if they improve life expectancy and/or quality of life. Trials aim to find out if a new treatment or procedure is safe, is better than the current treatment or helps you feel better. Read more at <http://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial>

You can also search for information on a number of websites and register your interest in taking part in research. The main ones are described below.

### UK Clinical Trials Gateway

The [UK Clinical Trials Gateway \(UKCTG\)](#) website pulls through information about clinical trials and other research from several different UK registers. If you sign up to it, researchers can contact you about research that might be suitable for you. You can also search the UKCTG site in various ways to find trials relevant to you, and you can contact researchers yourself.

### Charities

For some conditions, you can find out about clinical trials from the websites of charities.

Examples are:

- Cancer Research UK: [find a clinical trial](#)

## Are there any clinical trials I may be eligible for?

Trial	Eligible		Date discussed	With whom	Written information received
	Y	N			

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## Holistic Needs Care Plan (complete paper or electronic assessment prior to consultation)

Date:

Reviewed by:

Completed at:

diagnosis  start/end/change of treatment  discharge

Concern	Summary of discussion	Agreed Actions and Review Dates	Outcome and Date

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## Holistic Needs Care Plan (complete paper or electronic assessment prior to consultation)

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## LIVING WITH BLADDER CANCER – Smoking Cessation & Healthy Behaviours

ACTIONS (as appropriate based on person centred assessment)	Discussed with	Outcome of discussion
Your HCP will promote healthy behaviours including: eating 5 a day, reducing alcohol intake and incorporating exercise.		
Your Healthcare Professional (HCP) will ask you if you smoke as part of the clinical assessment process		
Your HCP will explain the link between smoking and bladder cancer, the benefits of stopping in terms of a lower risk of the bladder cancer coming back, as well as the benefits for your general health		
Your HCP will discuss with you and encourage a referral to a Smoking Cessation Service (people are four times more likely to stop smoking with NHS help)		
If you agree you will be referred to a local Smoking Cessation Service - <a href="http://www.nhs.uk/smokefree">www.nhs.uk/smokefree</a> - for a list of services in your area		
If you decline a referral initially, we will be happy to discuss this again at another opportunity		
Resources are available to help you stop smoking, which include: NHS Choices <a href="http://www.nhs.uk/smokefree">www.nhs.uk/smokefree</a> British Lung Foundation <a href="http://www.blf.org.uk">www.blf.org.uk</a> 0300 003 0555 Action on Smoking <a href="http://www.ask.org.uk">www.ask.org.uk</a> 0207 404 0242 Macmillan Cancer Support <a href="http://www.macmillan.org.uk">www.macmillan.org.uk</a> 0808 808 0000 Cancer Research UK <a href="http://www.cancerresearchuk.org">www.cancerresearchuk.org</a> 0808 800 4040		

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