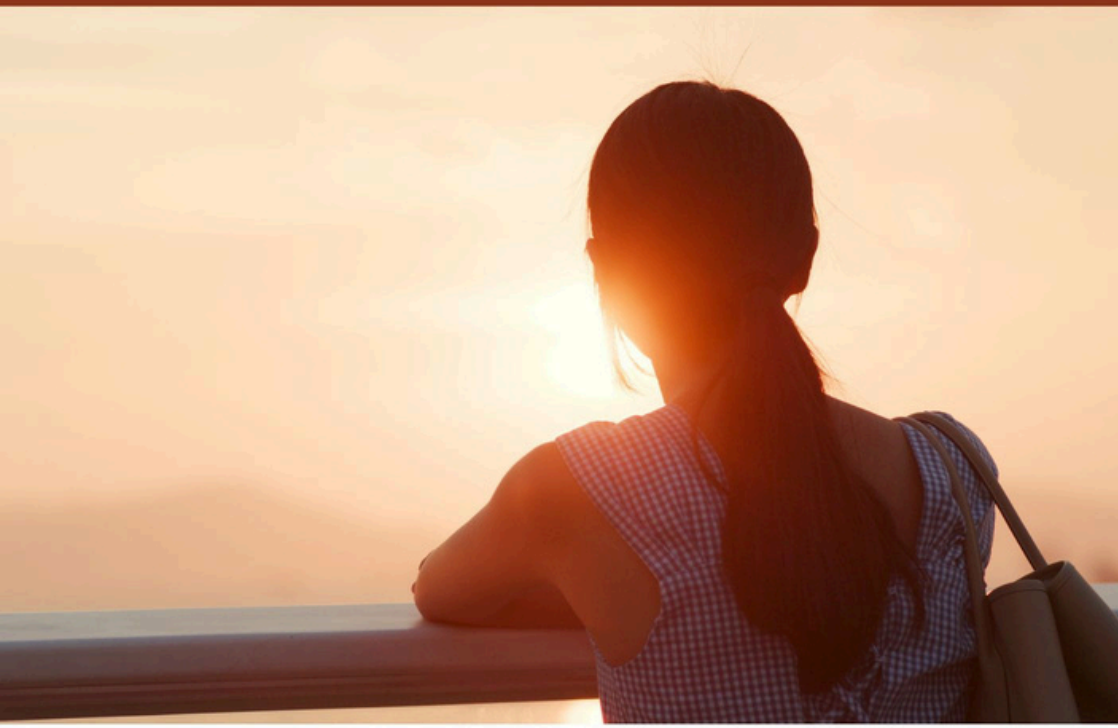
Kidney Cancer & You

Diagnosis

A supportive and informative guide for kidney cancer patients, carers, and families across the UK.



This booklet is created and published by **Kidney Cancer UK**

Contents

Thisbookletaimstogivegeneralinformationthatyoumayfindusefulbeforeandaftersurgery.Itis important to follow any specific advice given by your hospital and the material in this booklet.

Thefollowingindustrypartnerprovidedfinancialsupporttokidneycancerukto coverthecostsassociatedwiththe production and dissemination of this information booklet. All editorial control has been retained by Kidney Cancer UK.

Welcome

...to our Kidney Cancer & You Diagnosis booklet

To help you understand kidney cancer and the journey you are on, we have specifically designed this booklet for you to read at your leisure. We hope it will help inform you and your loved ones when you need guidance and information about kidney cancer and your diagnosis. This provides easy to understand scientific knowledge on kidney cancer, alongside practical information on living day-to-day with the disease and the range of emotions you may experience.

We understand that your experiences and treatments will be unique to you.

We hope the information and insights provided in this booklet will help you make informed choices in all areas of your journey and help you find support if, and when, you require it.

If you require support or have any questions on any aspect of kidney cancer care please ring our **Support Line** on **0800 002 9002.** In addition, we also run the following support services:

- Free Counselling service; please call **08000029002** or **01223 870 008** to arrange a consultation
- We provide closed Facebook Groups; find these by searching **'kidneycanceruksupportgroup'** or **'kidneycancerukmetastaticgroup'** or **'kidneycanceruksurgerygroup'** or **'kidneycancerukcarersgroup'**
- We present free to attend 'Living with kidney cancer' days in locations across the country and webinars on Zoom
- Kidney Cancer UK Online Support Groups, to find out more visit: **www.kcuk.org.uk/virtualonlinesupport/**
- And there are a number of local support groups around the UK please call **01223 870 008** or visit:
- **www.kcuk.org.uk/patient-support-groups** to find out more.

We are **'here to listen, inform and support'**

Kidney cancer

Thereareabout13,800newkidneycancercasesintheUKevery year, that's 38 every day (2017-2019)1. The incidence of kidney cancer has been steadily increasing in the UK. The rise in the number of tumours detected following a scan for unrelated conditions may have contributed to the rise in the numbers. Kidneycancerisnowthesixthmostcommoncancerinthe UK.

Kidneycancerandage

Kidneycancermoreoftenaffectsoldermen,whousuallyappear healthy; three quarters (75%) of people diagnosed with kidney cancer are over 60 years old and nearly twice as many men are diagnosed than women. It is not unusual to discover a tumour on the kidney incidentally whilst the patient is having a scan for an unrelated condition. It is uncommon for people under 40 to be diagnosed with kidney cancer 2,3.

Theriskofdevelopingkidneycancerstartstorisearound45-49 years and is highest in people aged 80-88 1. A risk factor is anything that increases a person's chance of developing cancer. Although risk factors can influence the developmentofcancer,mostdonotdirectlycausecancer.Some people with several risk factors never develop cancer, while others with no known risk factors do. However, knowing your risk factors and talking about them with your doctor may help you make more informed lifestyle and health care choices.

The most common early symptom is blood in the urine. If kidney cancerisdiagnosedatanearlystage,thereisagoodchanceofa cure by removal of the affected kidney to prevent the spread of the disease. The more the cancer has grown and spread throughout the body, the less chance that the treatment will cure the patient completely. However, treatment can often slow the progress of the cancer. Other symptoms can be less specific such as tiredness or pain. Some patients get no symptoms at all and the cancer is found incidentally.

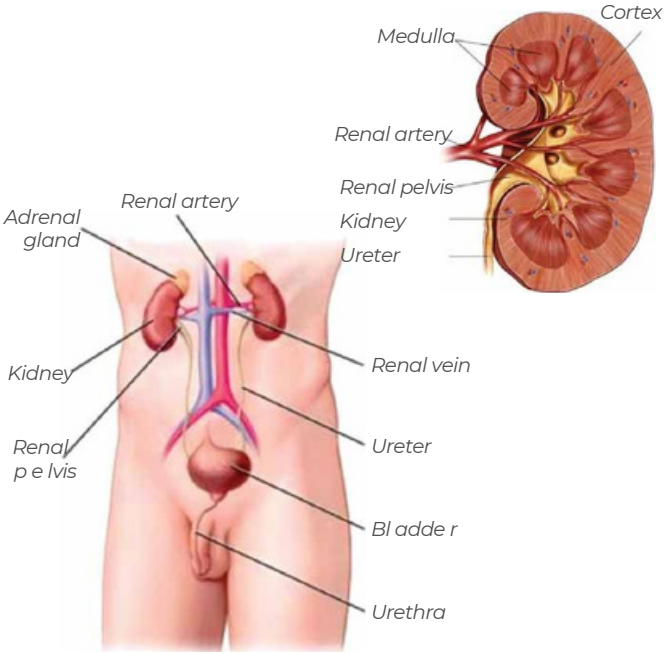
Riskfactorsfor kidney cancer 2

- Age; the risk of developingkidney cancerincreases withage
- Obesity
- Smoking
- Gender; men are nearly twice as likely to develop kidneycancerthan women
- Hypertension(high bloodpressure)
- Hereditarygenetic syndromes,suchas vonHippel-Lindau, Birt-Hogg-Dubé, tuberous sclerosis and hereditary leiomyomatosis renalcell carcinoma, caused by inherited genes
- Long term use ofmildpainkillers, suchasibuprofen (Nurofen®)
- Longtermkidney dialysis or renal

Typesofkidneycancer

The most common form ofkidney cancer is renal cell carcinoma or RCC for short. About 90% of kidney cancers are RCCs. There areseveraldifferentsubtypesofRCC,whicharenamedaccording to the type of cell that is affected or the appearance of the cancer cells under the microscope. The most common of these is clear cell, which account for about 75% of RCCs. Other subtypes include papillary, chromophobe, sarcomatoid and collecting duct carcinoma 4.

This booklet concentrates on RCC although some of the information should be helpful to any kidney cancer patient. Moreinformationaboutothertypesofkidneycancer,including transitionalcell(urothelial),Wilms'tumour,whichaffectsyoung children, and hereditary kidney cancer syndromes such as von Hippel-Lindau, Birt-Hogg-Dubé and tuberous sclerosis, can be obtained from our website **www.kcuk.org.uk**or from Cancer Research UK **www.cancerresearchuk.org**or Macmillan Cancer Support **www.macmillan.org.uk**



SubtypesofRenal Cell Carcinoma (RCC)

- Conventionalor clearcellRCC–this can also be called non-papillaryRCC and accounts for 75%ofRCCcases. The cancer cells appearclearunder themicroscopeand have large nuclei
- Papillaryor chromophilicRCC accountsforabout 10-15% of RCC cases.Thetumours havecharacteristic papillaeornodules on the surface
- Chromophobe RCCaccountsfor about 5% of cases
- Collectingduct carcinoma
- Renalmedullary carcinoma
- Mucinoustubular andspindle-cell carcinoma
- Renal translocation carcinomas
- UnclassifiedRCC, thelatterfiveof whichtogether make up the remaining5-10% ofRCCtumours

Receivingadiagnosis

Thesymptomsofkidneycancer

Themostcommonsymptomisbloodintheurine5,6,7.Doctors call this haematuria.

It may come and go and not every kidney cancer sufferer will have haematuria. For some patients the bleeding can be considerablesoyoushouldalwaysseekmedicalattention,the medical team will offer treatment if required.

Sometimesyouwon'tbeabletoseeit,butitcanstillbedetected byaurinetest.Mostpeoplewithbloodintheirurinedonothave kidney cancer. It can be a sign of an infection, kidney stones, prostate problems or bladder cancer. However, it should always be investigated to find out what has caused it.

Mostkidneycancersaretoosmalltofeel,butoccasionallyyou may feel a lump or mass in the area of your kidneys and you shouldtellyourdoctorstraightaway.Youshouldalsoseeyour doctoraboutanypersistentlowbackpainorpaininyourside betweenyourribsandhipbone(sometimescalledtheflankor loin)5,6,7.

In the early stages of kidney cancer there may be no obvious symptoms6,7.Manykidneycancersarefoundsimplybychance when someone is being given a scan for another reason. More than half of adult kidney tumours are detected when using an ultrasound scan to investigate other symptoms.

Sometimes abnormal red blood cell counts (anaemia) and high blood pressure, or hypertension, can be symptoms of kidney cancer 5. Occasionally some patients experience a condition called polycythaemia, or thickening of the blood, which can alsobeasymptomofkidneycancer.Symptomsofpolycythaemia are a bad headache and redness of the skin8.

In about a third of patients, the kidney cancer will have already spreadtootherorgans,suchasthelungs,liver,brainandbones. These patients may experience symptoms of advanced kidney cancer, such as a persistent cough, coughing-up blood (or haemoptysis),abnormalliverfunctiontests,headachesandvisual disturbances, or bone pain 6,8.

Typicalsignsand symptoms of kidney cancer

- Blood in the urine,alsocalled haematuria
- Persistentlow back pain or pain in the side betweentheribs andhipbone
- A lump or mass inthearea ofthe kidneys
- Abnormalred bloodcellcounts (anaemiaorrarely (polycythaemia)
- Highblood pressureor hypertension
- Tiredness
- Weightlossand/ or loss of appetite
- Runninga persistent temperatureand sweatingheavily, especiallyat night5,6,7

Thereareothersymptoms,whichcanbemoregeneralandcan also be caused by many other conditions, such as weight loss, tiredness and running a persistent temperature and sweating heavily, especially at night 6,7,8.

How doctors diagnose kidney cancer

Currently, there are no screening programmes for kidney cancer intheUK.Doctorsusetheirclinicalexperience(clinicalsuspicion), scans, and various tests to identify kidney cancer7,9,10.

At your GP surgery

YourfamilydoctororGPwillprobablycarryoutsomeinitialtests. He or she will ask about your general health, examine you and ask for a urine sample. This will be analysed to see if it contains blood. You may also be asked for a blood sample. This will be tested to see how well your kidneys are working. He or she may also perform a physical examination to check for any lumps or swelling; however, small tumours are difficult to detectonaphysicalexaminationbecausethekidneysaredeep inside the body.

Your GP may then refer you to a hospital specialist for further tests,especiallyifyouhavebloodinyoururine.Therearespecial referralguidelinesforGPstohelpthemdecidewhoneedstobe referred to a specialist urgently.

At hospital

The hospital specialist will want to know about your medical history,symptomsandanymedicationsyouaretaking.Ifanyone elseinthefamilyhashadkidneycanceryoushouldmentionthis. You will have more blood and urine tests, such as a full blood count(FBC)andureaandelectrolytes(U&Es),totestthefunction of your kidneys. If you want to know the results of your blood tests, please ask your doctor to explain them. Itisnotuncommonforpatientstohavetowaitafew weeks to be seen by a specialist.While waiting for an appointmentcanbeveryworrying,itisworthbearinginmind that if you do have kidney cancer, it is usually slow growing. It is also worth noting that while kidney cancer is suspected, around 20% prove to be benign tumours after investigation.

Your notes

Possibletestsyoumaybeaskedtohave

Ultrasoundscan

Asonographer will carry out an ultrasound scan, which is a real-time, moving test used to detect and differentiate between tumours and cysts on the kidney. This is a painless procedure that is carried out in the hospital scanning department andonly takes a few minutes to perform. You lie down and gel is spread ontherightandleftsideofyourabdomen.Asmallprobe,which producessoundwaves,isrubbed overthearea.Thesound wave echoesaredetectedbytheprobeandturnedintoapictureof the organs and structures inside your body by a computer.

Cystoscopy (bladder inspection)

Ifyouhavebloodinyoururine,yourdoctormightwanttocarry out a cystoscopy to check inside your bladder. The procedure is usually done under local anaesthetic. A fine, flexible tube with alightintheend(calledacystoscope)ispassedupyoururethra (waterpipe)andintoyourbladderwhereitactslikeatelescope allowing the doctor to see inside.

If the initial investigations confirm you have kidney cancer, you will need more tests to help doctors see if it has spread and how besttotreatit.However,someofthefollowingtestsmayalsobe used when your doctor is still trying to determine whether you have kidney cancer or not.

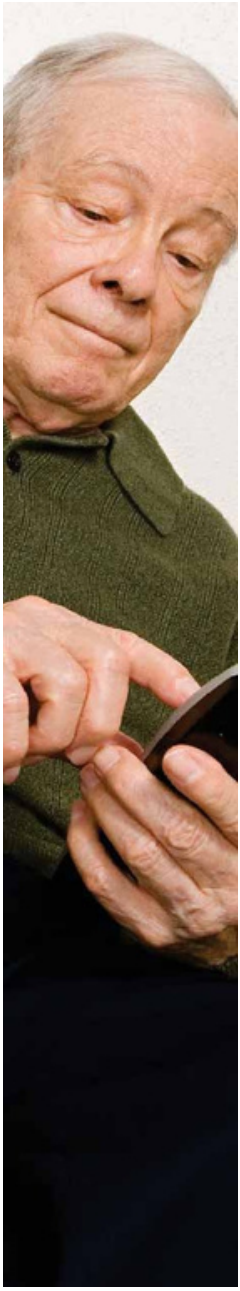
CT scan

Computerised tomography (CT) is a special type of X-ray examination and is conducted in the X-ray department of the hospital.ACTscanisusedtochecksizeofthetumourand whether it has spread to other organs, such as the lungs and the other kidney.

Questions you maywanttoask your doctor

- What tests are you going to do?
- Whatwillhappen andhowlongwill ittake?
- Will it be painful oruncomfortable whilsthaving thetestsor procedures?
- Will there be anyafter-effects oftreatmentsor interventions?
- Can I bring someone with me?
- Howlongwillthe resultstake?
- Whowillgiveme the test results?
- Willtheyshowif I have kidney cancer?
- Will they show ifthecancerhas spread?
- OnceIhavebeen diagnosedwhat happensnext?

The CT scanning machine takes a series of X-ray pictures of yourbodyfromdifferentangles.Acomputerputstheseimages togethertogiveadetailedimageoftheinsideofyourbody.You will need a full bladder for this examination, so you will not be abletogotothetoiletbeforehand.Themachineisshapedrather like a ring doughnut. You lie on a couch, which slides backwards and forwards through the hole. The radiographer cannot stay in the room with you during the scan but will be able to see you on a monitor and talk to you through an intercom. You may begivenaninjectionofaspecialdye,orcontrastagent,intoa vein in your arm to help blood vessels show up more clearly. You will need to drink water before and after the scan to flush the contrast through the kidneys. This can cause a shivery feeling throughyourbody.ACTscanispainlessbuttakeslongerthanan X-ray. The length of the whole procedure depends on how many pictures are taken butexpect to be on the couch for about 15 minutes.



Biopsy

Doctors can usually make a diagnosis from a CT scan alone. Sometimes a biopsy will also be carried out. Using ultrasound or CT scan to locate the kidney, a thin needle is put through the skin and muscle into the kidney to remove a small sample of tissue. This is then examined under a microscope to checkforsignsofcancer.Youwillneedtobeobservedforabout 4 hours after the biopsy. You will be given a local anaesthetic to numb the skin.

MRI scan

Magnetic resonance imaging (MRI) is a type of scan that uses magnetism instead of X-rays to construct a detail picture of the inside of your body. MRI is used to check the size and extent of a tumour, and to determine whether or not the cancer has spread to other organs of the body. You may be given an injection of special dye or contrast agent into a vein in your arm to help the tumours show up more clearly on the MRI scan picture. Some people feel a little claustrophobic during a scan. If you think you might,telltheradiographersbeforethedayofyourappointment. The MRI scan is very loud,and you will be given ear coverings, it normally lasts for 30 minutes to 1 hour.

Bone scan

Youmight be asked to have a bone scan to see whether the cancer has spread to your bones. If so, you will be injected with a mildlyradioactivematerial andthenaskedtowaitforacoupleof hours while it travels though the blood and collects in the bones. Areas where there is damage to the bone will show up as 'hot spots'. These aren't necessarily the result of cancer. If you have arthritis, for instance, this will also show up on the scan.

ChestX-ray

A chestX-ray may be carried out to check your general health andmakesurethatyouarefitenoughtohavecertaintreatments or surgery. It will also be used to rule out cancer spread to the lungs or chest bones. However,you may not have a chest X-ray if you have a CT scan that has included your chest on the scan.

You will have a follow up appointment with your consultant to discuss your results. This may take a little while and you will probably feel worried and upset during this time. Is there anyone you canshare your feelings with? Is there a clinical nurse specialist you can talk to? It might be useful to use our support servicessuchastheSupportLine,supportgroupsandcounselling service.

Staging and grading kidney cancers

Beforedoctorscandiscussappropriatetreatmentoptionswith you,they need to know how far your suspected cancer has progressed andhow quickly the cancer might be growing or spreading. This is called staging and grading.

Staging is used to describe how big a cancer is and how far it has already spread. Information from the tests and scans used todiagnoseyourcancerisusedtodeterminethestageofyour disease.

TheTNMsystemisacommonsystemusedforstaging tumours 11,12

T (tumour)plusanumberindicatesthesizeoftheprimary tumourandhowfarithasgrown:Thenumberrefersto the stages described below:

TXmain tumour cannot be measured

T0thereis noevidence ofprimary tumourin the kidney

T1thetumourislessthan7cminsizeandiscompletely contained within the kidney

T1aisatumourlessthan4cm insize

T1bisatumourbetween4and 7cminsize

T2thetumourismorethan7cminsizeandiscompletely contained within the kidney

T2ais atumour more than7 cm butless than 10cm in size

T2bis atumour morethan 10cm insize

Your notes

Receiving a diagnosis

T3 the cancer has spread beyond the kidney to the tissues or organs around the kidney, for example a major vein or the adrenal gland

T3a is a tumour that has grown into the renal vein or the fat surrounding the kidney

T3b is a tumour that has grown into the vena cava below the diaphragm

T3c is a tumour that has grown into the vena cava, or the wall of the vena cava, above the diaphragm

T4 the cancer has spread beyond the tissues or organs around the kidney to more distant organs in the body

N (nodes) plus a number indicates that the cancer has spread to nearby lymph nodes. The number refers to the number of affected lymph nodes:

NX cancer in nearby lymph nodes cannot be measured

N0 cancer has not been detected in any lymph nodes

N1 cancer has spread to one nearby lymph node only

N2 cancer has spread to more than one nearby lymph node

Doctors often call lymph nodes that contain cancer, positive lymph nodes. The lymph nodes nearest to the kidney include the paraaortic, renal hilar and caval lymph nodes

M (metastases) plus a number refers to place elsewhere in the body where the cancer has spread.

MX means there are no distant metastases

M0 metastases cannot be found

M1 means distant metastases are present

Your doctor will combine these figures to give an overall staging, e.g. T2 N0 M0, which means the cancer is bigger than 7 cm but still confined to the kidney, there is no involvement of lymph nodes and there are no metastases.

Your notes

Another staging classification which is sometimes used for kidney cancer is a number system; the cancer is simply said to be stage 1, 2, 3 or 4 (or stage I, II, III, or IV). Again, the stages reflect how large the primary tumour has become, and whether the cancer has spread to lymph nodes or other areas of the body. A stage 4 tumour is often referred to as an advanced cancer. The number system used for kidney cancer is as follows:

Stage 1
The cancer is confined to the kidney and is less than 7 cm in size.

Stage 2
The cancer is bigger than 7 cm but still confined to the kidney.

Stage 3
The cancer has started to spread outside the kidney to the adrenal gland or a major vein nearby. The cancer may have spread to no more than one nearby lymph node.

Stage 4
The cancer has spread to nearby tissues or organs and more than one nearby lymph node contains cancer cells OR the cancer has spread to other parts of the body further away.

Finding the stage of a cancer helps doctors to advise on what is the best treatment and gives them a reasonable indication of the outlook (prognosis) for a cancer. It also describes the cancer in a standard language which is useful when doctors discuss patients, and when patients are involved in clinical trials. When discussing the treatment options, the doctor will also take into account how well you are overall.

Your notes

Doctorsgradecancerstoindicatehowquicklyorslowlyacancer is likely to grow and spread. Cells from a sample of the cancer (a biopsy) are looked at under the microscope or tested in other ways.Bylookingatcertainfeaturesofthecellsthecancercanbe graded as low, intermediate or high grade; this system is called the Fuhrman system 12,13

Grade1orlow-gradecellsareusuallyslowgrowing,lookquite similar to normal cells, tend to be less aggressive and are less likely to spread.

Grade2orintermediategradecellsgrowmorequickly,look abnormal, are moderately aggressive and could spread.

Grade 3 or high-grade cells are likely to grow more quickly, lookveryabnormal,tendtobemoreaggressiveandaremore likely to spread.

Grade 4 or high-grade cells look very abnormal, grow very quickly,areextremelyaggressiveandareverylikelytospread.

Discussingtreatmentoptions

Ideally, a team of specialists, called a multi-disciplinary team (MDT),willberesponsibleforyourcareandtreatment.Theteam will include a urologist (a doctor who specialises in diagnosing and surgically treating urinary, bladder and kidney problems), radiologists, oncologists and specialist nurses. Preferably, all will have experience of treating kidney cancer. The urologist and, if appropriate, the medical oncologist will be responsible for your treatment and will discuss your treatment plan with you. Other members of the team may include a dietician, a physiotherapist(forpostoperativecomplications),anoccupational therapist and a psychologist or counsellor. The team might also include a clinical oncologist (a doctor specialising in radiotherapy treatment for cancer) if you are scheduled to have radiotherapy for cancer that has spread.

Your notes

Ifneeded,your doctors will tell you which treatment they think would be best for you. Sometimes they may offer you a choice of treatments. In any case, you should be sure you have been given enough information, and understood it, before you give permissionforthetreatmenttostart.Don'tbeembarrassedabout asking people to explain things again. And remember to ask about any aspects that are worrying you.

Pembrolizumab (Keytruda) is approved in the UK as an optional adjuvant treatment of renal cell carcinoma, for patients at increased risk of recurrenceafternephrectomy,withorwithoutmetastaticlesionresection.

14

Clinical Trials

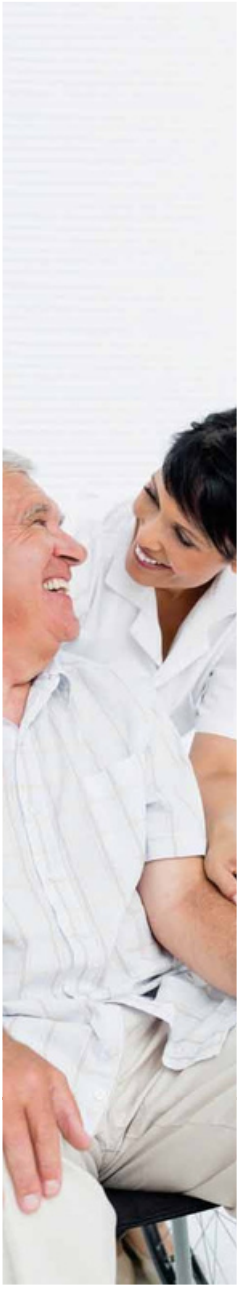
You might be offered a clinical trial as part of your treatment. When doctors are uncertain about whether one type of cancer therapy is better than another, or if a new treatment or drug is likely to work or have side-effects, they try to answer this by involving patients in clinical trials. During a clinical trial, detailed informationiscollectedabouteachpatient,drugside-effectsand how well the treatment has worked.

You should be told at your follow up appointment

- Whattypeoftreatmentthedoctorsareadvising
- How and when this would be carried out
- Theadvantagesanddisadvantagesofthistypeoftreatment
- Any possible other treatments that might be available
- Any significant risks or side effects of the treatment

Itmaybeusefultowritedownalistofquestionstotakewithyou to any appointment. It is also a good idea to have a relative or friend with you when you are discussing your treatment options. They will be able to take notes or help you remember what was said. If you feel you can't make a decision straightaway, askfor more time to decide.

Youmaywantasecondopinion;especiallyifyoufeelyourdoctor does not have enough experience in treating kidney cancer or if you are told little beneficial treatment is available. Most doctors will be willing to refer you to another specialist, but it may take a little while to organise. As this may delay thestart of your treatment you need to feel sure it will be worthwhile.



Formoreinformationabouthowtogetasecondopinionvisitour website **www.kcuk.org.uk/second-opinion-on-diagnosis/**

You may find the decision to go ahead relatively easy, if the treatmentyouarebeingofferedaimstocureyourcancer.Butif, instead, the aim of the treatment is to control the cancer for a period of time, it may be more difficult to decide.

You might want to think about your quality of life while you arehavingtreatment.Willyouhavetotravelbackandforthto hospital?Whatarethesideeffectsoftreatment?Cantheside effects be treated?

Aswellastalkingthingsoverwiththepeoplewhomeanmostto you, you may find it helpful to talk to a counsellor or a specialist nurse. If you choose not to have treatment you can still be given help to control any symptoms you have. This is called palliative care and can be offered to help patients through their entire cancer journey. Palliative care also gives people support with social, spiritual and psychological issues. Carers and family may also be offered emotional and spiritual support as well.

Beingtoldyoumighthavekidneycancerisalwaysa shock

Peoplereactindifferentways.Somewanttofindoutasmuchas they can about their treatment and their long-term prospects. Othersdon'twanttothinkaboutthefuture,preferringtotake eachdayasitcomeswithoutworryingaboutwhatmayormay not lie ahead.

Itisnormaltohaveanxietyupondiagnosisofkidneycancerand there are various ways to support you with this. Speak to your medical team or ring our **Support Line** on **0800 002 9002**.

Yournotes

As doctors know only too well, it can be very difficult to predict what will happen because every patient is an individual. Of course, the earlier cancer is detected,and the sooner treatment begins, the better the chances of long-term survival. Even if cancerhasspread,makingitmoredifficulttotreat,itispossible for the symptoms to be kept well under control for years. And in some rare cases patients may go into remission for no apparent reason.

What happens next?

Onceadiagnosishas beenmadeyouwill bereferredto either aUrologysurgicalteamoranOncologyteamandinmanycases a specialist clinical nurse.

You may find it useful to read one of these booklets depending on your diagnosis.

You can download a copy from our website **www.kcuk.org.uk/library/** or call **01223 870 008** to request one.

Your notes

Supportandinformation

Money matters

Financial advice

For financial advice please contact your local Citizens Advice Bureau who will be very happy to support you. Search 'Citizens Advice Bureaux' in your web browser for your local office.

A specialist nurse or health professional will be able to advise you about other grants that are available for you. These can beformobilityaidsortohelpwith heating costsorhouseholdexpenses relatedto yourillness.Aspecialistnurse orhealth professionalwillalsohelpyou claimany benefits you are entitled to. A number ofmeanstested,andnon-meanstested benefitsmightbe available,depending on your circumstances. Many hospital departments also have a social worker who can provide helpful information.

Advice regarding Personal IndependencePayment(PIP)

PatientswholiveinNorthernIrelandshould consult:

www.nidirect.gov.uk/information-and-services/benefits-and-money/benefits-and-financial-support

Support

Family and friends

People who are close to you may find it difficulttodiscussyourillness.Youmaybe afraid that if you talk to people about how you really feel they will be upset, or disappointed at your lack of stoicism, or embarrassed because they don't know whattosay.Butitisimportanttobeable toexpressyourfeelingswhenyouneedto. It can also be difficult talking to children about cancer. How much should you tell them? How honest should you be?

Other support

Sometimesitcanbeeasiertotalkthings through with someone outside the family.Thiscouldbeaspecialistadviseror someonewhohasgonethroughasimilar situation and knows how you are feeling.

www.kcuk.org.uk

Kidney Cancer UK offers a dedicated free to call telephone **Support Line (0800 002 9002)**, where you can talk tooneofourHealthProfessionalnurses withexperienceofkidneycancer.Ifyou leave a message out of hours someone willcallyouback.Youcanalsoapplyto join our very popular closed Facebook groupsbysearching **kidneycanceruksupportgroup**, or **kidneycancerukmetastaticgroup** or **kcuksurgerygroup** or **'kidneycancerukcarersgroup'**

Youcouldalsojoinalocalsupportgroup if there is one in your area, to find out call **01223 870 008** or visit www.kcuk.org.uk/patient-support-groups/

Self-help

Regular exercise can help you feel better both physically and emotionally. Ask your doctor or nurse what kind of exercise would be suitable for you. Visit our website www.kcuk.org.ukwhere under patientinformationyouwillfindresources for mindfulness, exercise and diet.

Wheretofindmoreinformation and support

Kidney Cancer UK and Kidney Cancer Scotland are the UK's leading kidney cancercharities.Weofferinformationand support to kidney cancer patients, their families and carers not only via a comprehensive website and closed facebook support group, but also via regular online support groups on Zoom.

We also assist with establishing local patientgroups,bringingpatientstogether to share their experiences.

Call Kidney Cancer UK **01223 870 008** (9am –5pm Monday to Friday)

Or visit **www.kcuk.org.uk**

Maggie's Centres

Maggie'sofferfreepractical,emotional and social support to people with cancer and their families and friends.

www.maggiescentres.org

MacmillanCancerSupport

Call Macmillan nurses on **0808 808 0000** (9am –8pm, Mon –Fri) or visit **www.macmillan.org.uk**

MarieCurieCancerCare runs hospices throughout the UK and provides a nationwide Marie Curie nursing service. Marie Curie nurses provide free nursing care to cancer patients and those with other terminal illnesses in their own homes. Call the help line for patients and carers on **0800716146** or visit **www.mariecurie.org.uk**

Help, information and support can also befoundatlocalhospital-basedsupport groups. Please ask your doctor or nurse for more information.

References

If reading on a computer, please copy and paste the link into your browser rather than clicking on the link as it may not work.

1 Cancer Research UK: Kidney cancer incidence statistics. **www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer#heading-Zero** Accessed September 2024.

2 Cancer Research UK: Risks and causes of kidney cancer. **www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/kidney-cancer/risk-factors** Accessed April 2022.

3 Macmillan Cancer Support: Types of kidney cancer. **www.macmillan.org.uk/Cancerinformation/Cancertypes/Kidney/Aboutkidneycancer/Typesofkidneycancer.aspx** Accessed April 2022.

4 Renal and Urology News: Classifying Histologic Subtypes of Renal Cell Carcinoma, LR Harik and MA Ordonez, March 2011. **www.renalandurologynews.com/classifyinghistologic-subtypes-of-renal-cellcarcinoma/article/197648/** Accessed April 2022.

5 NHS Choices: Kidney cancer. **www.nhs.uk/conditions/Cancer-of-the-kidney/Pages/Introduction.aspx** Accessed April 2022.

6 Cancer Research UK: Symptoms of kidney cancer. **about-cancer.cancerresearchuk.org/about-cancer/kidney-cancer/symptoms** Accessed April 2022.

7 Macmillan Cancer Support: Symptoms and diagnosis of kidney cancer. **www.macmillan.org.uk/information-and-support/kidney-renal-cancer/understanding-cancer/signs-and-symptoms.html#268629** Accessed April 2022.

8 Patient.co.uk: Kidney cancer. **www.patient.co.uk/health/kidney-cancer** Accessed April 2022.

9 Cancer Research UK: Diagnosing kidney cancer. **about-cancer.cancerresearchuk.org/about-cancer/kidney-cancer/getting-diagnosed** Accessed May 2020.

10 NHS Choices: Diagnosing kidney cancer. **www.nhs.uk/conditions/kidney-cancer/diagnosis/** Accessed April 2022.

11 AJCC Cancer Staging Manual, Seventh Edition (2010) published by Springer-Verlag New York, **www.springer.com/gb/book/9783319406176** Accessed April 2022.

12 Escudier, B, Eisen, T, Porta, C et al. Renal cell carcinoma: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up. Annals of Oncology 23 (supplement 7): vii65-vii71 2012.

13 Macmillan Cancer Support: Staging and grading of kidney cancer. **www.macmillan.org.uk/Cancerinformation/Cancertypes/Kidney/Symptomsdiagnosis/Staginggrading.aspx** Accessed April 2022.

14 **www.nice.org.uk/guidance/ta830/chapter/1-Recommendations**

Glossary

Adjuvant treatment
Atreatmentgivenaftersurgerytolower the risk of cancer returning.

Advanced cancer
This usually meansa cancer has spread from where it started to another part of thebody.'Locallyadvanced'cancerusually means the cancer has grown outside the organ that it started in and into nearby body tissues.

Biopsy
Removalofasmallpieceofbodytissueso that the cells can be looked at under a microscope.

Birt-Hogg-Dubé(BHD)syndrome
Arareinherited genetic condition that ischaracterisedbyskinlesionsontheface and neck. It is caused by a genetic mutation in the folliculin gene. Patients mayalsodeveloplungcystsorexperience a collapsed lung, and a few develop kidney cancer.

Bone scan
Adiagnostictestusingamildlyradioactive material to see whether the cancer has spread to your bones.

Catheter
Tubethatispassedintothebodytodrain fluid.

Cells
Every part of the body is made up of specialised,individualcells.Cancerstarts with one cell becoming cancerous.

Chromophobe RCC
Asubtypeofrenalcellcarcinoma,which accounts for 5% of RCC cases.

Clear cell RCC
Themostcommonsubtypeofrenalcell carcinoma, which accounts for 75% ofRCCcases.Thecancercellsappear clear under the microscope and have large nuclei.

ClinicalNurseSpecialist(CNS)
An advanced practicenurse witha graduatequalification;clinicalexpertsin the diagnosis and treatment of illness.

Clinical Oncologist
Adoctorwhospecialisesinradiotherapy treatment for cancer.

Clinical trial
A rigorouslycontrolled research study that finds new ways to prevent, diagnose or treat disease. Clinical trials test new treatmentsinpeoplewithcancertomake suretheyaresafeandeffectiveattreating cancer.

Collecting duct carcinoma
Asubtypeof renal cellcarcinoma, which developsinthecellsthatlinethecollecting ducts in the kidney cortex.

Glossary

Computerised Tomography (CT)
A specialtypeofX-rayexaminationwhere a series of X-ray pictures of your body are taken from different angles and put togetherbyacomputertogiveadetailed image of the inside of your body.

Contrast agent
A specialdyewhichisgivenduringan X-ray, CT or IVU/IVP as an injection or in a drink.Contrastagentsareopaquetox-rays andareusedtogivesofttissuesandblood vessels contrast on an X-ray so that they can been seen.

Cryoablation
Cryotherapy(Cryoablation)killsthecancer cells by freezing the tumour.

CyberKnife (gamma knife) cystoscopy
Aninvestigationofthebladder.Asurgeon putsatube(orcystoscope)intothe bladder and uses it to look inside the bladder and urethratocheckifthereis anythingwrong.

Diagnosis
Finding out what is wrong.

Dialysis
Anartificialwayoffilteringwasteproducts and excess water from your blood when your kidneys can't.

Fuhrman system
Asystemusedforgradingrenalcellcancer toindicatehowquicklyorslowlythecancer is likely to grow and spread.

Full Blood Count (FBC)
Abloodtest which provides important information about the type, number and appearanceofcellsintheblood,especially red blood cells, white blood cells, and clotting cells.

Gr ade
Doctorsgrade cancers to indicate how quicklyorslowlyacancerislikelytogrow and spread. Cells from a sample of the cancer(abiopsy)arelookedatunderthe microscope or tested in other ways.

Haematuria
The presence of blood in the urine.

Haemoptysis
Coughing-up blood.

Hypercalcaemia
High levels of calcium in the blood.

Hypertension
High blood pressure.

Lymph nodes or glands
Glandswhichfightinfectionandfilterbody fluid (lymph).

Magnetic Resonance Imaging (MRI)
A type of scan that uses magnetism instead of X-ray to construct a detail picture of the inside of your body.

Medical Oncologist
A doctor who specialises in the medical treatment of cancer.

Metastases or secondaries
Areas of cancer spread.

Multidisciplinary Team (MDT)
A group of health care and social care professionals who provide different services for patients in a co-ordinated way. Members of the team may vary and will depend on the patient's needs and the condition or disease being treated.

Neuropathic pain
Pain that comes from problems with the signalling from nerves.

Oncology and Oncologist
The study and treatment of cancer. An oncologist is a doctor who specialises in the diagnosis and treatment of cancer.

Palliative care
Treatment given to control symptoms and improve quality of life rather than to cure. Includes support for social, spiritual and psychological issues.

Papillary (or chromophilic) RCC
A subtype of renal cell carcinoma, which accounts for about 10-15% of RCC cases. The tumours have characteristic papillae or nodules on the surface.

Percutaneous
A medical procedure carried out or occurring through the skin.

Physical examination
The process by which a doctor investigates the body of a person for signs of disease.

Polycythaemia
Thickening of the blood caused by an increase in red blood cells due to an abnormality in the bone marrow, or a decrease in the volume of plasma, the fluid which carries the red blood cells.

Primary cancer (primary tumour)
Where the cancer started. The type of cell that has become cancerous will be the primary cancer; for example, if a biopsy from the liver or lung contains cancerous kidney cells, then the primary cancer is kidney cancer.

Prognosis
The likely outlook for someone with a disease.

Glossary

Quality of life
Thismeanslookingathowatreatmentis affectingyourlife,notjusttheeffecton your cancer.

Recurrence
Cancerthathascomebackagainafter treatment.

Remission
Ifa canceris in remission, there is no sign ofitonscansorwhenthedoctorexamines you. Doctors use the word 'remission' insteadofcurewhentalkingaboutcancer becausetheycannotbesurethatthereare no cancer cells at all in the body.

Renal Cell Carcinoma (RCC)
A type ofkidneycancerthat originates in the lining of the proximal convoluted tubule,theverysmalltubesinthekidney that filter the blood and remove waste products. RCC accounts for 90% of kidney cancers.

Secondary cancer
Cancerthathasspreadtoanotherpartof the body from the place where it started (primary cancer). Secondary cancers (tumours) are the same type of cancer as theprimarycancer.Alsocalledsecondaries or metastases.

Staging
Asystemusedbydoctorstodescribehow bigacancerisandhowfarithasalready spread.

SABR(Stereotacticablativebody radiotherapy)
Thisisahighlypreciseformofradiotherapy used to treat kidney cancer.

Tuberous sclerosis
Ageneticdisordercharacterised by abnormalitiesoftheskin,brain,kidneyand heart.

Tumour
Aswellingorlesionformedbyanabnormal growthofcells.Tumourisnotsynonymous with cancer and a tumour can be benign (not cancerous) or malignant (cancerous).

TNM staging
Asystemfor staging cancer based on thepresenceoftumours(T),lymphnode involvement (N) and metastases (M).

Transitional Cell Carcinoma (TCC)
Atypeofcancerthatdevelopsinthelining of the bladder, urethra and renal pelvis.

Ultrasound scan
Areal-time,movingtestwhichusessound wavestodetectanddifferentiatebetween tumours and cysts. A small probe producingsoundwavesisrubbedoverthe areaofinterestandthesoundwaveechoes are detectedbytheprobeandturnedinto a picture of the organs and structures inside your body by a computer.

Urea and Electrolytes (U&E)
Abloodtestwhichteststhefunctionof the kidneys.

Ureter
Thethin tube or duct that carries urine fromthekidneytothebladder,whereitis stored.Therearetwoureters,oneattached to each kidney.

Urology and urologist
Thestudy and treatment of the urinary tractinwomenandtheurogenitalsystem in men. An urologist is a doctor who specialises in the diagnosis and treatment ofdiseasesoftheurinaryandsexorgansin males and the urinary organs in females.

Wilms' tumour
Averyrarekidneycancerwhichaffects children.

X-ray
Atypeofelectromagneticradiationused to make images. The image is recorded on a film, called a radiograph. The parts of your body appear light or dark due to thedifferentratesthatyourtissuesabsorb the X-rays. Calcium in bones absorbs X-raysthemost,soboneslookwhiteon theradiograph.Fatandothersofttissues absorb less and look grey. Air absorbs least, so lungs look black.

Hospital appointments

Date **Time**

Location

Notes

Date **Time**

Location

Notes

Date **Time**

Location

Notes

Date **Time**

Location

Notes

Date **Time**

Location

Notes

Date **Time**

Location

Notes

Date **Time**

Location

Notes

Date **Time**

Location

Notes

Your notes

Your notes

Edition 3.6
Last reviewed: October2025
Next review: October2027

Grateful to
ThisbooklethasbeenpreparedwiththeassistanceofDrKateFife,Consultant,ClinicalOncologist and Dr Natalie Charnley, Clinical Oncologist.

Edited by
Hazel Jackson Kidney Cancer UK Healthcare Nurse from Kidney Cancer UK. TheCharityis appreciativetopatientsthatalsoassisted in its review.

Yourdonationisessential to the work we carry out

We receive no government funding and are dependent on your donations whilst also raising money from other sources. How could youorsomeone youknow helpus and make adifference?

- SET UP A MONTHLY DONATION
- LEAVE US A GIFT IN YOUR WILL
- ORGANISE A FUNDRAISING EVENT
- TAKE PART IN ONE OF OUR CAMPAIGNS
- VOLUNTEER

Withyourgeneroussupportwecancontinueto invest in patient support and research. Without research, the treatment patients receive today will be the treatment they receive tomorrow.

Pleasevisitourwebsiteformoreinformationabouthowyou cansupportourwork**www.kcuk.org.uk/donate**orreturn the formbelowviaFreeposttosimply**'Kidney Cancer UK'** or ring **01223870008**wherewewillbehappytohelpyou.

Name

Address

Town

Postcode

Email

Telephone

Please tell me more about

- ○ Donating
- ○ Making a gift in my will
- ○ Volunteering
- ○ Add me to your mailing list

Kidney Cancer UK

THE UK'S LEADING KIDNEY CANCER CHARITY

Website: www.kcuk.org.uk

Our Free Support Line: 0800 002 9002
(open Mon-Fri, 10am-2pm)

Our mission:

Kidney Cancer UK is the UK's leading charity dedicated to kidney cancer. Our mission is to minimise the impact of the disease by raising awareness, providing vital patient information, and supporting research into its causes, prevention, and treatment.

Follow us @kidneycanceruk

Health & care information you can trust

The Information Standard Certified Member