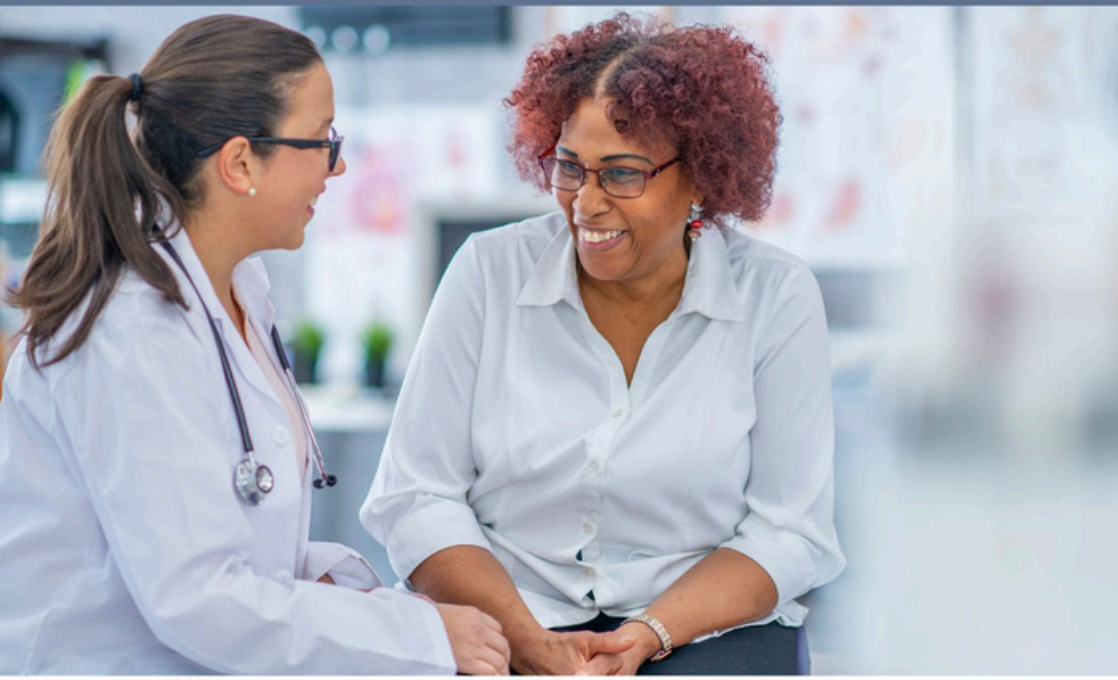
Kidney Cancer & You

Metastatic treatments

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



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This booklet aims to give general information that you may find useful before and after surgery. It is important to follow any specific advice given by your hospital and the material in this booklet.

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MERCK

Welcome

...toour'Kidney Cancer & You –MetastaticTreatments' booklet

Tohelp you understand kidney cancer and thejourney you are on, we have specificallydesignedthisbookletforyoutoreadatyourleisure.Wehopethis booklet will help inform you and your loved ones when you need guidance andinformationabouttreatments.Thisprovideseasyto-understandscientific 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 makeinformedchoicesinallareasofyourjourneyandhelpyoufindsupport if, and when, you require it.

Ifyourequiresupportorhaveanyquestionsonanyaspectofkidneycancer care please ring our **Support Line** on **0800 002 9002.** In addition, we also run the following support services:

- FreeCounsellingservice;pleasecall**08000029002**or **01223870008** toarrangeaconsultation
- WeprovideclosedFacebookGroups;findthesebysearching **'kidneycanceruksupportgroup'** or **'kidneycancerukmetastaticgroup'** or
- **'kidneycanceruksurgerygroup'** or **'kidneycancerukcarersgroup'** Wehoastfreetoattend'Livingwithkidneycancer'daysinlocations
- across the country and webinars on Zoom

  Online support group sessions, to find out more visit:
- **www.kcuk.org.uk/virtualonlinesupport/**

  Andthereareanumberoflocalsupportgroupsaroundthe UKplease call **01223 870 008** or visit:

Weare **'heretolisten,informand support'**

KidneyCancer

EveryyearintheUK,over13,834peoplelearnthat they have kidney cancer1. The incidence of kidney cancer has been steadily increasing in the UK.

Anincreaseinthenumberoftumoursdetectedwhen a patient has a scan for an unrelated condition may have also contributed to the rise in the number of kidney cancer cases. Approximately 50% of kidney cancer diagnoses are found incidentally.

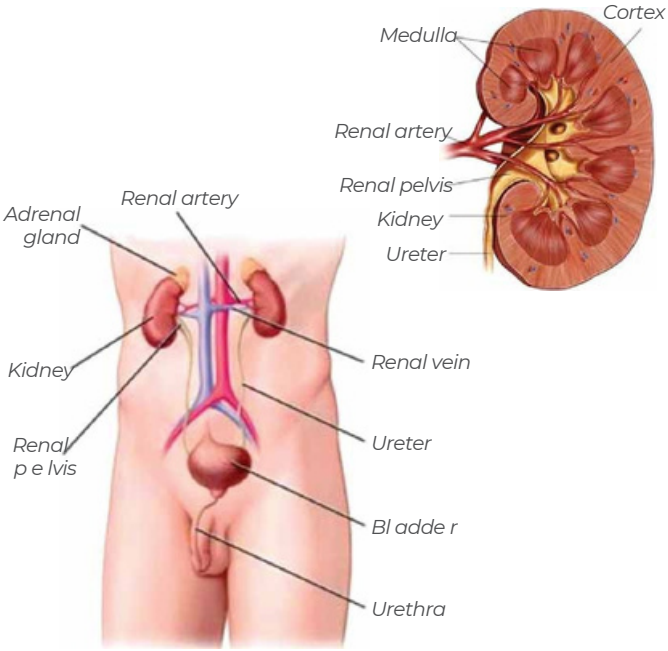
Kidneycancerisnowthesixthmostcommon cancerintheUKandaccountsfor4%ofallnew diagnoses of cancer 1.

Your notes

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, sarcomatoidand collecting duct carcinoma 2.

This booklet concentrates on RCC although some of the informationshouldbehelpfultoanykidneycancerpatient.More informationaboutothertypesofkidneycancer,includingWilms' tumour, which affects young 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**



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 accountsfor about 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
- Renaltranslocation carcinomas
- UnclassifiedRCC, thelatterfiveof whichtogether make up the remaining5-10% ofRCCtumours

Stagingandgradingkidneycancers

Beforeyourdoctorscandiscusstreatmentoptionswithyouthey need to know how far your cancer has progressed and how quicklythecancerisgrowingorspreading.Thisiscalledstaging 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.

TheTNMsystem(Tumor, Node, and Metastasis) isacommon systemusedforstagingtumours and can generally be found in the letter from your pathology report 3, 4

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

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 there are no cancer cells in the 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

Understanding your treatment

Anotherstagingclassificationwhichissometimesusedforkidney 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 spreadtonomorethanonenearbylymphnode.Stage3isoften referred to as locally advanced kidney cancer.

Stage 4
Thecancerhasspreadtonearbytissuesororgansandmorethan one nearby lymph node contains cancer cells, orthe cancer has spread to other parts of the body further away.

Finding the stage of a cancer helps doctors to advise on what is thebesttreatmentandgivesthemareasonableindicationofthe outlook(prognosis)foryourcancer.Italsodescribesthecancerin a standard language which is useful when doctors discuss patients, and when patients are involved in clinical trials. When discussing your treatment options, your doctor will also take into account how well you are overall.

Doctorsgradecancerstoindicatehowquicklyorslowlyacancer is likely to grow and spread. Cells from a sample of the cancer (known as a biopsy) are looked at under the microscope or tested in otherways.Bylookingatcertainfeaturesofthecells, thecancercanbe graded as low, intermediate or high grade 4, [5]

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), will be responsible for your care and treatment in the cancer unit. The team will include a urologist (a doctor who specialisesindiagnosingandsurgicallytreatingurinary,bladder andkidneyproblems)and,ifyourcancerhasspread,amedical oncologist who specialises in the medical treatment of cancer. Preferably,bothwillhaveexperienceoftreatingkidneycancer. Theurologistand,ifappropriate,themedicaloncologist,will be responsible for your treatment and will discuss your treatment plan with you.

Your notes

Other members of the team may include a clinical nurse specialist(specialistnurse),adietician,aphysiotherapist(forany postoperative complications), an occupational therapist and a psychologistorcounsellor.Theteammightalsoincludeaclinical oncologist (a doctor specialising in radiotherapy treatment for cancer) if you are scheduled to have radiotherapy for cancer that has spread.

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 givenenoughinformation,andunderstoodit,beforeyougive permission for the treatment to start. Don't be embarrassed aboutaskingpeopletoexplainthingsagain.Andrememberto ask about any aspects that are worrying you.

Youshouldbetold

- Whattypeoftreatmentthedoctorsareadvising
- How and when this would be carried out
- Theadvantagesanddisadvantagesofthistypeoftreatment
- Any possible other treatments that might be available
- Anysignificant risksor sideeffects ofthe treatment

It may be useful to write down a list of questions to take with you to the 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 whatwassaid.Ifyoufeelyoucan'tmakeadecisionstraightaway, ask for 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 alittlewhiletoorganise.Asthismaydelaythestartofyour treatment you need to feel sure it will be worthwhile.

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?
- Oncelhavebeen diagnosedwhat happensnext?

Thereismoreinformationabouthowtogetasecondopinion on our website by searching for **'Second Opinion'.**

Youmightwanttothinkaboutyourqualityoflifewhileyouare having treatment.

- Whatarethepracticalitiesandfinancialrequirements associated with travelling to and from hospital?
- Whatarethesideeffectsoftreatment?
- Can the side effects be treated?

Aswellastalkingthingsoverwithclosefamilyandfriendsyou may find it helpful to talk to a counsellor or a specialist nurse. Ifyouchoosenottohavetreatmentyoucanstillbegivenhelp tocontrolanysymptomsyouhave.Thisiscalledpalliativecare andcanbeofferedtohelppatientsthroughtheirentirecancer journey. Palliative care also gives people support with social, spiritual and psychological issues. Carers and family members may also be offered emotional and spiritual support. See page 20 for more on palliative care.

Treatmentforadvanced (Metastatic)kidneycancer

Kidney cancer that has spread around the body, or is too extensivetoberemovedsurgically,iscalledadvanced(Stage4) kidney cancer.

There is a huge variation in the rate of spread of kidney cancer. Occasionally it grows very quickly over the space of a few months,andinotherpeopleslowlyovermanyyears.Treatments therefore will be different and individualised to you.

Sometimes observation is recommended, rather than active treatment,especiallyifacancerisgrowingslowly.Yourspecialist will be able to explain all the options to you. This is known as active surveillance.

Surgery

Forsome patients, even if the cancer has spread, the kidney tumourmaystillbetakenoutifitiscausingproblems,andif the secondary tumours are fairly small (See our Surgery and Recovery Booklet).

Your notes

Understanding your treatment

Your oncology team will tailor your treatment to your specific typeofkidneycancerandwhattheybelievewillhavethemost benefit for you.

It is important when taking any treatment to tell them about anysideeffectsthat youmayhavesotheycanhelpyoumanage andtreatthem.Yourclinicalnursespecialistordoctorshould giveyou an emergency contact number to ring if you are worried about side effects at any time. You also need to tell your medical team about any other medications you are taking, including vitamins, supplements and over the counter remedies.

Standard chemotherapy is ineffective in most advanced kidney cancer. Treatment for kidney cancer use biological therapies, these are drugs that act on a specific process within the cells, andareusedtokillthecancercellsorstopthemfromgrowing. These treatments can shrink the cancer or control it for a number of months to years. There is a great deal of research happeningtofindoutwhycertainpatientsdowellonaspecific treatment and which is the best combination of drugs togive topatientswithadvanceddisease.Youcangetmore information about clinical trials from our website www.kcuk.org.uk/clinicaltrials

Severaldifferentbiologicaltherapiesareusedforthetreatment of advanced kidney cancer, including immunotherapies and targeted treatments.

Your notes

Targeted treatments

Cancer researchers havebeen working to find new ways of treatingkidneycancer.Oneofthemostpromisingadvancements in the last decade has been the development of targeted therapies;suchastyrosinekinaseinhibitors(TKIs)andmammalian target of rapamycin (mTOR) inhibitors. These drugs are now standard of care treatment for advanced Kidney cancer.

TyrosineKinasesinhibitors (TKIs)

Drugs such as **Sunitinib** (Sutent®), **Pazopanib** (Votrient®), **Axitinib** (Inlyta®), **Tivozanib** (Fotivda®) and **Cabozantinib** (Cabometyx®) areTKIs.Thesedrugsblocktheeffectsofaprotein called tyrosine kinase, which is involved in new blood vessel growth, essential for cancer cells to divide and grow. These treatments starve the tumour by stopping the development of a new blood supply (angiogenesis). These types of medications are called anti-angiogenic agents. Tyrosine kinase inhibitors also interfere with the growth of cancer cells by blocking the signals withinthecancercellsthattellthemtogrowanddivide,causing the cancer cells to die 6, 7.

Tyrosinekinaseinhibitorscomeastabletsorcapsulestakenorally. **Sunitinib** comes as a capsule, which is taken once a day for four weeks followed by a two-weekbreak. **Pazopanib** comes in a tablet form and is taken once a day in continuous cycles of six weeks. **Axitinib** is a tablet and is taken twice a day, ideally 12 hours apart, this treatment is continuous. **Tivozanib** is an oral tablet taken daily, 3 weeks on and 1 week off. **Cabozantinib** is an oral tablet taken daily. All the treatments may come as severaltabletsorcapsulestomakeupthedoseyouarerequired to take. TKIs are taken until they are no longer effective or side effects are unacceptable.

Common side-effectsofTKI'S include

- Tiredness
- Diarrhoea, nauseaand vomiting
- Skin and hair discolouration/ changes
- Redblistered handsandfeet, soremouth
- Anincreasein blood pressure
- Thyroidproblems
- Bloodproblems
- Loss of taste and appetite

Many of these side-effectscanbe controlledwith medicationand may do not affect everyone, you might onlyhave oneortwo side-effects. A side-effect may get worse through your course of treatment,ormore may develop as the course goes on.

Mammaliantargetofrapamycin(mTOR)
mTORisatypeofproteincalledakinaseprotein.Itcanmake cells produce chemicals (such as cyclins) that trigger cell growth. It may also make cells produce proteins that trigger the development of new blood vessels. Cancers need new blood vessels in order to grow 6, 7.

Everolimus (Afinitor®) is an mTOR blockers (inhibitors) used in advanced renal cancer. Everolimus is an oral tablet, taken once daily.

Everolimus is used in combination with a TKI called **Lenvatinib** (Lenvima®). Lenvatinib is given as capsules once daily, with an Everolimus tablet also once daily.

Immunotherapies

Immunotherapies are used in advanced kidney cancer to stimulatetheactionoftheimmunesystemtorecognisethat cancer is present 8.

Drugtreatments availableonthe NHS (some are dependant on country)

- Sunitinib (Sutent®)
- Pazopanib (Votrient®)
- Axitinib (Inlyta®)
- Bevacizumab (Avastin®)
- Cabozantinib (Cabometyx)
- Lenvatinib (Kisplyx)with Everolimus
- Tivozanib (FOTIVDA®)
- Avelumab (Bavencio)with (Inlyta)
- Pembrolizumab (Keytruda)and Axitinib(Inlyta®)
- Nivolumab (Opdivo)
- Interleukin-2or Aldesleukin (Proleukin)
- Nivolumab (Opdivo)with Ipilimumab (Yervoy)

Monoclonalantibodies

Nowbeingwidelyusedinadvancedkidneycancermonoclonal antibodies. This type of treatment stimulates the body's immunesystemtofightcancercells.Theyrecogniseandblock a protein receptor on the immune T-cells called PD-1 or PDL1 or CTLA-4. **Nivolumab** (Opdivo®) targets and blocks a protein called PD-1 on the surface of certain immune cells called T-cells. Blocking PD-1activatestheT-cellstofindandkillcancercells.Nivolumab is administered through a drip into a vein every two to four weeks for up to an hour depending on dose and frequency. It is generally well tolerated. The most common side effects associatedwithnivolumabareimmune-mediatedinflammatory conditions such as inflammation of the colon, lungs, liver, kidney, skin and thyroid. The side effects are treatable by your clinical team.

Common side-effectsassociated with Nivolumab include

- Immunemediated inflammatory conditions
- Inflammationof thecolon,lungs, liver,kidney,skin andthyroid

Theseside-effects aretreatablebyyour clinicalteam.

Nivolumab and **Ipilimumab** (Yervoy®) is a combination immunotherapytreatment.Ipilmumabtargetsadifferentprotein CTLA-4. In this combination, Ipilmumab works together with Nivolumab to help shrink the tumour. The side effects of the combination are similar to Nivolumab alone.

Avelumab (Bavencio) and **Axitinib** (Inlyta®) is a combination immunotherapy and TKI treatment. Avelumab targets the PDL1 protein and works similarly to Nivolumab. Whilst Axitinib targets the VEGF pathway, as previously described. With this dual action thereisgreaterimpactuponthetumourtoshrink.Sideeffectsof Avelumab are similar to Nivolumab.

Pembrolizumab (Keytruda) and **Axitinib** (Inlyta®) is another immunotherapy and TKI combination. Pembrolizumab targets thePD1proteinandworkssimilarlytoNivolumabandAvelumab. Whilst Axitinib targets the VEGF pathway, as previously described. With this dual action there is greater impact upon the tumour to shrink. Pembrolizumab (Keytruda) is approved in the UKasanoptionaladjuvanttreatmentofrenalcellcarcinoma,for patients at increased risk of recurrence after nephrectomy, with or without metastatic lesion resection.11

Cabozantanib and Nivolumab
Cabozantanib(Cabometyx)andNivolumab(Opdivo)isapproved in the UK for previously untreated patients with stage 4 kidney cancer with intermediate or poor risk.

Belzutifan
Belzutifan (Welireg) is now approved for patients with Von HippelLindaudisease.Thisisthefirsteverdrugapprovedforthis condition and is a breakthrough for patients. Previouslytheonlytreatmentwasinvasivesurgeryand radiotherapy.

Your notes

Newtreatmentsarecontinuouslyreviewedbygoverning bodies in the specific countries of the UK:

NICE England,WalesandNorthernIreland
SMC Scotland
AWTCC Wales(additionalguidance)
DoH NorthernIreland (additional guidance)

Fertility

All drugs used to treat cancer can affect fertility. If you are prescribed drugs they may only affect your ability to have children while you are taking them. However, with newer treatments, the long-term effects may not yet be known, so this isanimportantissuetodiscusswithyourdoctorbeforeyoustart treatment. If you are concerned about this please speak to your consultant. Itmay beappropriateforyoutobereferredforspermoregg banking.

Other treatments

Radiotherapy

RadiotherapyuseshighenergyX-raystodestroycancercells. Radiotherapy may be used to help control and alleviate the symptoms of advanced kidney cancer. It may be used if the cancerhasspreadtootherareasofthebody,suchasbones, the brain, lungs 9.

Itcanbeusedtoshrinkalargetumourandrelievepressureon nearby organs.

Treatmentisgiveninthehospitalradiotherapydepartmentand will be tailored to you. Some people have daily treatments (or fractions) from Monday to Friday for a few weeks. Others may need only one or two treatment fractions (sessions).

Radiotherapycanbedirectedattheareaofthebodycontaining the tumour so as to kill most of the cancer cells and avoid as muchhealthytissueaspossible.Theactualtreatmentonlytakes afewminutesanddoesnothurt.Youwillbeabletotalktothe radiographer via an intercom if you need them.

Side-effectscanincludefatigue,nauseaandvomiting,and sore or red skin. They take a while to build up and usually persist for a few days after the treatment has finished. Yourdoctorwillbeabletotellyouwhattoexpectandhow to cope.

If your cancer has spread to your brain, radiotherapy can be very successful at controlling symptoms and slowing down the growth of the cancer. It can be given in a number of different waysandisusuallygivenincombinationwithsteroids.Howitis given depends mostly on the size and number of areas of cancer spread in the brain. If there are only one or two areas affected, it may be treated with stereotactic radiotherapy (also called radiosurgery or gamma knife surgery or CyberKnife) using high doses ofradiation directed at the cancer using a head frame. Only a single treatment is required.

Ifthecanceriswidespread,thereisthepossibilityofthespread of cancer cells throughout the brain, which are too small to detect on a scan. In this case whole brain radiotherapy is used. This is usually given in 5 fractions over a week or 10 fractions over 2 weeks 4, 5. Stereotactic body radiotherapy can now be used to treat metastases found in the liver, lung and pancreas, as well as the brain.

Oligometastatic renal cancer

Oligometasticdisease means one or a few secondary localised tumour(s) arising from the primary tumour. It can sometimes be appropriate to consider localised treatment to these rather than generalised treatment to the whole body such as chemotherapy.

To treat a brain tumour metastasis:

Patientsmayhavesurgerytoremovethetumourorstereotactic radiosurgery. Radiosurgery is a type of stereotactive radiotherapy.Itinvolvesveryhighdosestereotacticradiotherapy as a single fraction, or up to 5 fractions.

To treat a lung metastasis:
Lung tumours could be treated by microwave ablation, thetumourcouldbesurgicallyremovedorbySABR(stereotactic body ablation radiotherapy)

Radio frequency ablation
Radiofrequencyablationworksbyusingheattodestroycancer cells.Thistreatmentisatypeofthermalablation,whichcanbe used to cure, reduce the size or relieve pain of a cancer10.

Cryotherapy (Cryoablation)
Cryotherapykillsthecancercellsbyfreezingthetumour.Itcan beusedtotreatmetastases(secondarytumours)inthekidneys and helps to preserve normal functioning kidney tissue. Please refer to our Cryotherapy fact sheet on our website for more information.

New treatments

Medical researchers across the world are constantly working ondiscoveringnewandmoreeffectivewaysoftreatingkidney cancer,aswellastryingtofindoutthecausesofkidneycancer and how to prevent it. All treatments need to be vigorously tested before they are allowed onto the market to ensure they are safe, effective at treating cancer, and work better thancurrenttreatments.Testingnewtreatmentsisdonein clinical trials. For more information about clinical trials, pleasetakealookattheKidneyCancerUKwebsitesearch; 'Clinical Trials'.

Thefollowingnewtreatmentsarebeinginvestigatedin clinical trials:

New targeted therapies including immunotherapies are continually in development. Most clinical trials at the momentareinvestigatingnewtyrosinekinaseinhibitors in combination with monoclonal antibodies.

Your notes

Understanding your treatment

Questions you might like to ask your team

- Wherewillllhavemytreatment?
- What will it involve?
- Howlongwillittake?
- How will it affect me?
- What help will I get to deal with side-effects?
- Willlevergetbacktonormalorwilltherebesome long-term effects?
- Will I be able to go back to work?
- What is the aim of this treatment?
- Willthetreatmentcuremy cancer?
- Will the treatment stop the cancer growing or spreading?
- Whatarethe risksofthis treatment?
- What are the advantages of this treatment?
- What will happen if I don't have this treatment?
- Will I be able to manage with just one kidney?
- Whathappensifmyotherkidneystopsworking?
- Whatistheriskofgettingcancerintheotherkidney?
- What follow-up assessments will I have and when?
- Howdo Igo aboutenrolling ona clinical trial?
- How do I get access to non-NHS drugs if I need them?
- Arethereanylocalsupportgroupsatthehospital or in my area?

Your notes

Living with kidney cancer

Feelings

If you are told you have cancer it can be hard to take everything in. It can be doubly hard if you are being told your cancer has already spread and cannot be cured, or that a cancer you thought had gone has come back.

You will probably go through a whole range of emotions, such as: shock and fear, sadness and anger, disbelief and numbness. You might find yourself thinking: 'Why me?', or 'this can't be happening to me!'. There is no right or wrong way to feel; everyone reacts differently. Some people want to share their feelings and worries with their partner, their family or close friends. Others prefer to come to terms with the news first before talking to others.

It is very common to wonder if things you did or didn't do in the past are to blame for you getting ill. But it isn't usually possible to tell exactly what caused a person's cancer and you may have to accept this. However, some people find they feel much less helpless and more in control if they learn as much as they can about the cancer itself and the ways it can be treated. Even if your cancer cannot be cured, there are ways of slowing it down or stopping it altogether for a time. Treatments can also help reduce or take away any symptoms you have been getting.

Day-to-day living

Your health professionals are experts at controlling symptoms and often liaise between patients, relatives, GPs and the hospital to improve quality of life for the whole family. Some are qualified counsellors. Marie Curie nurses and healthcare assistants also provide support at home.

Your notes

Kidney Cancer UK
Support line
& Counselling booking
0800 002 9002
Call free

Living with kidney cancer

Look after your kidneys and cut down on the amount of salt in yourdiet,eathealthilyandatallstagesduringyourkidneycancer journey, a healthy, well-balanceddiet will help you maintain strength and prevent infection and do wonders for your overall health and well-being. Good nutrition and maintaining calories is especially important when you are undergoing intense treatments, such as surgery, radiotherapy and drug treatments. If you are a smoker, try to stop. There are many aids to help you and your doctor will be delighted to support you. Keep alcohol consumption to a minimum, drink plenty of water, and don't take large doses of vitamin C supplements.

Fatigue(tiredness)isoneofthemostdistressingside-effectsand maybecausedbymanyfactors,includingdepression,insomnia, anemia, the effects of cancer treatment, and the cancer itself.

To help with fatigue, you need to pace your activities and organise your home and work environments in a way to help accommodate lower energy levels. Regular, gentle exercise and a healthy diet will help to reduce fatigue. As will relaxing activities, suchasreading,listeningtomusic,watchingTV,andtakinganap during the day.

Wehavelotsofadviceonourwebsite www.kcuk.org.uk; Search **'wellbeing'.**

Palliative care

Palliative care attempts to make the end of a person's life as comfortableaspossiblebyattemptingtorelievepainandother distressing symptoms, while providing psychological, social and spiritualsupport.Palliativecarecanbeasupportiveandpositive option when the cancer is no longer curable; it should not only be considered in the terminal phases of illness. You may need access to palliative care services almost from the point of diagnosis,particularlyforhelpindealingwithsocial,spiritualand psychological issues. Carers and families may also be offered emotional and spiritual support.

Palliativecarecanbeofferedinyourownhome,inahospice (residential or day care) or in hospital. If you decide to stay at home your GP or Oncologist can arrange for community palliativecarenurses,suchasMacmillanorMarieCurienurses,to provide care at home. The social services department may need to be contacted to provide a range of social care services and equipment to help you remain at home.

Specialist palliative care teams, such as the Macmillan support team,symptomcontrolteamorpainmanagementteam,provide palliative care in hospitals or hospices. These teams include doctors, nurses, physiotherapists, dieticians, social workers, complementary therapists and chaplains, or the service can be provided by a specialist nurse.

Palliativecareteamshelptomanageyoursymptomsandenhance your feeling of wellbeing. There are a number of support services availabletopatientswhoarelivingwithincurablecancerthatcan help to improve quality of life. For example, Marie Curie offer a range of therapies that patients can access at their hospices for a few hours, or by attending a specific clinic. These therapies includeacupuncture,aromatherapy,massage,reflexology,and shiatsu, which help patients relax and improve their feeling of wellbeing.

Your notes

Support and information

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 Bureau' in your web browser for your local office.

A specialist nurse or health professional will be able to advise you about other grantsthatareavailableforyou.These can beformobilityaidsortohelpwith heating costs or household expenses related to your illness. A specialist nurse or health professional will also help you claim any benefits you are entitled to. A numberofmeanstestedandnon-means tested benefitsmightbeavailable, depending on your circumstances. Many hospital departments also have a social worker who can provide helpful information.

Advice regarding Personal Independence Payment (PIP)

Patients who live in Northern Ireland shouldconsult:

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

Your notes

Support

Family and friends
People who are close to you may find it difficulttodiscussyourillness, andyou may be 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 what to say. But, it is important to be able toexpressyour feelingswhenyouneedto. It can also be difficult talking to children about cancer. How much should you tell them? How honest should you be? You could also speak to our Counsellor about these

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

KidneyCancerUKoffersadedicated 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 groups by searching:

'kidneycanceruksupportgroup' or
'kidneycancerukmetastaticgroup' or
'kidneycanceruksurgerygroup' or
'kidneycancerukcarersgroup'

Youcouldalsojoinalocalsupportgroupif there is one in your area, call **01223870 008** or visit **www.kcuk.org.uk/patient-support-groups/** to find out.

Also, we hold regular online support sessionsonZoom,whetheryouarehaving surgery or have metastatic kidney cancer there are different sessions to support everyone, visit:

www.kcuk.org.uk/virtualonlinesupport/

to find out more information.

Self-help
Regularexercise can help you feel better both physically and emotionally. Ask your doctorornursewhatkindofexercisewould be best. Many people find that complimentary therapies, such as massage, aromatherapy, meditation or visualisation, can also lift the spirits, ease tension and restore a feeling of wellbeing.
You could look at our website www.kcuk.org.uk/virtualonlinesupport/ and search **'wellbeing'** where we have many free useful resources.

Support and information

Wheretofindmoreinformation and support
KidneyCancerUKandKidneyCancer ScotlandaretheUK'sleadingkidneycancer charities.Weofferinformationandsupport to kidney cancer patients, their families and carers not only via a comprehensive website and closed Facebook support group, but also regular online support groups.

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

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

Kidney Cancer Support Line is a dedicatedtelephonehelplinefromKidney Cancer UK and Kidney Cancer Scotland thatprovidessupportandencouragement to kidney cancer patients, their families and carers. Call **0800 002 9002** (Monday to Friday, 10am to 2pm. Bank holidays 10am to Noon, except Christmas and Boxing Day) or visit **www.kcuk.org.uk**

Kidney Cancer UK Counselling Service
The UK's first dedicated kidney cancer counselling service is now available. You can find our more and how to book an appointment by visiting our website and searching 'counselling' or call our free Counselling service on **0800 002 9002** or **01223 870 008.**

www.kcuk.org.uk

Cancer Research UK
Call **Cancer Help** on **0808 800 4040** (9am –5pm, Mon-Fri) or visit **www.cancerresearchuk.org/cancer-help/**

Maggie's Centres
Maggie'soffersfreepractical,emotional andsocialsupporttopeoplewithcancer andtheirfamiliesandfriends.Visit **www.maggiescentres.org**

MacmillanCancerSupport
CallMacmillannurseson**08088080000** (9am –8pm, Mon-Fri) or visit **www.macmillan.org.uk**

Marie Curie Cancer Care runs hospices throughout theUK 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.Callthehelplineforpatients carerson **0800 716 146** or visit **www.mariecurie.org.uk**

National Institute for Health and Care Excellence (NICE) clinical guideline CG27. Referralguidelinesforsuspected cancer.IssuedJune2005.ModifiedJanuary 2018.

NHS conditions: Kidney cancer:
www.nhs.uk/conditions/kidney-cancer/

Help, information and support can also be found at local hospital-based support groups.Pleaseaskyourdoctorornursefor more information.

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

12 www.nice.org.uk/guidance/ta964/chapter/1-Recommendations

Glossary

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.

Angiogenesis
Growthofbloodvessels.Growingcancers can attract new blood vessels to grow towards them so that they can get their own blood supply.

Anti-angiogenic agents
Agentswhichinterferewiththe development of blood vessels.

Arterial embolisation
Aprocedureinwhichthebloodsupply totheareaofthekidneycontainingthe tumour is blocked causing it to shrink.

Bilateralrenalcellcarcinoma/ kidney cancer
Renalcellcarcinomaorkidneycancer affecting both kidneys.

Biological therapy
Treatmentthat uses natural body substances,ordrugsmadefromnatural body substances to treat cancer.

Biopsy
Removal of a small piece of body tissue sothatthecellscanbelookedatundera microscope.

Birt-Hogg-Dubé (BHD) syndrome
Arareinherited genetic condition that is characterised by skin lesions on the face andneck.Itiscausedbyageneticmutation in the folliculing gene. Patients may also develop lung cysts or experience 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 clearunderthemicroscopeandhave large nuclei.

Clinical Nurse Specialist (CNS)
An advanced practicenurse with a graduatequalification;clinicalexpertsin the diagnosis and treatment of illness.

Glossary

Clinical Oncologist
Adoctorwhospecialisesinradiotherapy treatment for cancer.

Clinical trial
A rigorouslycontrolled research study thatfindsnewwaystoprevent,diagnose or treat disease. Clinical trials test new treatmentsinpeoplewithcancertomake suretheyaresafeandeffectiveattreating cancer.

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

Combination therapy
Usingtwoormoretypesoftreatment eg surgery and chemotherapy or chemotherapy and radiotherapy.

Computerised Tomography (CT)
AspecialtypeofX-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
Aspecialdyewhichisgivenduringan 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.

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

Diagnosis
Finding out what is wrong.

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

Fuhrman system
Asystemusedforgradingrenalcellcancer to indicate how quickly or slowing the cancer 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.

HighIntensityFocusedUltrasound(HIFU)
Amethod ofkilling cancer cellsby directing a strong beam of sound at the tumour.Thistechniqueiscarriedoutusing aprobethroughtheskintherebyavoiding open surgery.

Hypercalcaemia
High levels of calcium in the blood.

Hypertension
High blood pressure.

IMDC
The international metastatic renal cell carcinomadatabaseconsortium(IMDC)isa system used to predict outcomes and guidetreatmentdecisionsforpatientswith stage 4 RCC.

Lymph nodes or glands
Glandswhichfightinfectionandfilterbody fluid (lymph).

Magnetic Resonance Imaging (MRI)
Atypeofscanthatusesmagnetisminstead of X-rays to construct a detail picture of the inside of your body.

Medical Oncologist
Adoctorwhospecialisesinthemedical treatment of cancer.

Metastases or secondaries
Areas of cancer spread.

Multidisciplinary Team (MDT)
A group of health care and social care professionalswhoprovidedifferentservices for patients in a co-ordinated way. Membersoftheteammayvary,andwill dependonthepatient'sneedsandthe condition or disease being treated.

Nephrectomy
Surgicalremovalofakidney.Eitherradical (thewholekidneyandsurroundingtissues) or partial.

Neuropathic pain
Painthatcomesfromproblemswiththe signalling from nerves.

Oncology and Oncologist
The study and treatment of cancer. An oncologistisadoctorwhospecialisesinthe diagnosis and treatment of cancer.

Palliative care
Treatmentgiventocontrolsymptomsand improvequalityofliferatherthantocure. Includes support for social, spiritual and psychological issues.

Partialnephrectomyorkidney/ nephronsparingsurgery
Surgical removal of part of the kidney containingthetumourtokeepasmuch normalkidneytissueaspossible,sothat thereducedkidneyisstillabletowork.

Papillary (or chromophilic) RCC
A subtype of renal cell carcinoma, which accountsforabout10-15%ofRCCcases. Thetumourshavecharacteristicpapillaeor nodules on the surface.

Percutaneous
Amedicalprocedurecarriedoutor occurring through the skin.

Glossary

Physical examination
Theprocessbywhichadoctorinvestigates thebodyofapersonfor signsofdisease.

Polycythaemia
Thickening of the blood caused by an increase in red blood cells due to an abnormality in the bone marrow, or a decreaseinthevolumeofplasma,thefluid which carries the red blood cells.

Primary cancer (primary tumour)
Wherethecancerstarted.Thetypeofcell that has become cancerous will be the primary cancer; for example, if a biopsy fromtheliverorlungcontainscancerous kidney cells, then the primary cancer is kidney cancer.

Prognosis
Thelikelyoutlookforsomeonewitha disease.

Quality of life
Thismeanslookingathowatreatmentis affectingyourlife,notjusttheeffecton your cancer.

Radical nephrectomy
Removalof thewholekidney and surroundingfattytissue,theadrenalgland, and nearby lymph nodes.

Radiotherapy
Atreatmentusinghigh-energyraysto destroycancercells.Itcanbeusedto shrinkakidneycancerandsocontrol symptoms.

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.

Second-line treatment
Treatmentgivenwhenfirst-linetreatment doesn'twork,orstopsworking,orcauses severe side effects.

Secondary cancer
Cancerthathasspreadtoanotherpart ofthebodyfromtheplaceinwhichit started(primarycancer).Secondarycancers (tumours) are the same type of cancer as theprimarycancer.Alsocalledsecondaries or metastases.

Staging
A system used by doctors to describe how big a cancer is and how far it has already spread.

SABR (Stereotactic ablative body radiotherapy)
This is a highly precise form of radiotherapy used to treat kidney cancer.

Tuberous sclerosis
A genetic disorder characterised by abnormalities of the skin, brain, kidney and heart.

Tumour
A swelling or lesion formed by an abnormal growth of cells. Tumour is not synonymous with cancer and a tumour can be benign (not cancerous) or malignant (cancerous).

TNM staging
A system for staging cancer based on the presence of tumours (T), lymph node involvement (N) and metastases (M).

Transitional Cell Carcinoma (TCC)
A type of cancer that develops in the lining of the bladder, urethra and renal pelvis.

Ultrasound scan
A real-time, moving test which uses sound waves to detect and differentiate between tumours and cysts. A small probe producing sound waves is rubbed over the area of interest and the sound wave echoes are detected by the probe and turned into a picture of the organs and structures inside your body by a computer.

Urea and Electrolytes (U&E)
A blood test which tests the function of the kidneys.

Ureter
The thin tube or duct that carries urine from the kidney to the bladder, where it is stored. There are two ureters, one attached to each kidney.

Urology and urologist
The study and treatment of the urinary tract in women and the urogenital system in men. A urologist is a doctor who specialises in the diagnosis and treatment of diseases of the urinary and sex organs in males and the urinary organs in females.

Wilms' tumour
A very rare kidney cancer which affects children.

X-ray
A type of electromagnetic radiation used to make images. The image is recorded on a film, called a radiograph. The parts of your body appear light or dark due to the different rates that your tissues absorb the X-rays. Calcium in bones absorbs X-rays the most, so bones look white on the radiograph. Fat and other soft tissues absorb less and look grey. Air absorbs least, so lungs look black.

Hospital appointments

Date **Time**

Location

Notes

Date **Time**

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Your notes

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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.

Pleasevisitourwebsiteformoreinformationabouthowyoucan supportourwork**www.kcuk.org.uk/donate**orreturntheform below via Freepost ~~by writing~~ **'Freepost Kidney Cancer UK'** on the envelope or ring **01223 870 008** where we will be happy to help you.

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

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