

Kidney Cancer & You

For Carers & Families

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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Introduction

Your Friend

We understand that kidney cancer knows no boundaries, it touches wives, husbands, brothers, sisters, loved ones, family members, and relatives. So, for ease and simplicity within this booklet, we will refer to them as a collective noun throughout because, as a carer, this is what they must be to you; *'friend'*. We mean no disrespect and hope all wives, husbands, brothers, sisters, loved ones, family members, or relatives living with kidney cancer will understand this simplification, just for the purpose of this booklet.

TIP

- Keep it simple

Caring for your friend

When finding out someone you know has kidney cancer, most people want to help and offer themselves out selflessly; *“is there anything I can do?”* and this is a wonderful gesture. Embrace and act on the reply you get. Most importantly, do not under any circumstances, fire up Google and start researching kidney cancer. The information you find will not be relevant to your patient and will often be incorrect. If you must research online, use **www.kcuk.org.uk** as your starting point, we will have all the answers you need. Later in the booklet you will read about a patient’s ‘keyworker’ also known as their ‘medical team’ or ‘CNS’ (Clinical Nurse Specialist). Always refer to them with any questions, they know the patient, they know the case, they have the notes.

You can gain a better understanding about kidney cancer by visiting our website where you will find a wealth of information plus our free ‘Understanding Kidney Cancer’ series of booklets. We have three titles: ‘Diagnosis’, ‘Treatments’ and, ‘Surgery & Recovery’. All are available free in hard copy or to read online. We also have a number of informative fact sheets available.

Remember to listen to the patient and treat them generally as you would normally. No one wants to feel like a burden or that they are making you feel restricted or uncomfortable.

But you might not know what you can do. Or you may have trouble finding the right words when speaking to them. Many times we have heard of friends retreating into the background and not talking to the patient. This could be for many reasons, they could be so upset they simply can’t talk about it, they may not understand any of what has happened and don’t want to look silly, or they might not know how to talk to the patient for fear of saying something insensitive or damaging. This kind of withdrawal can leave the patient feeling like they are facing kidney cancer alone.



Top-line overview of anticipate pathway

The patient may be given options for treatment and feel overwhelmed and find it difficult to decide. If you can read any information provided by your friend's medical team it should give you enough knowledge to know what each treatment entails, the recovery period and what help they will require following surgery/treatment. Discussing the treatment options together, you may both also want to seek further information and support from the patient's key worker helping your friend make an informed treatment choice.

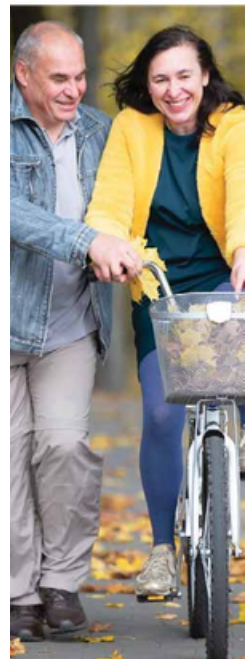
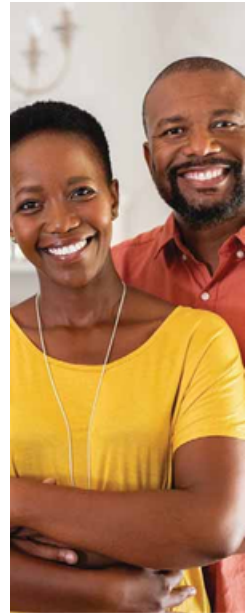
Once the patient has made a treatment decision for surgery or ablation, he/she will be added to a waiting list. The waiting time for surgery differs across the country therefore it is advisable that approximate wait times are discussed with the surgeon.

A diagnosis

How can I support my friend who has kidney cancer?

Having a friend who has kidney cancer diagnosed can be hard to cope with for you, family, and friends as well as the patient. You might feel helpless and lacking control over what's happening. Friends and family may well want answers to questions as well – questions you don't know the answers to.

While you are talking to the consultant, they are very likely to use some very long and complicated words, and he may use a lot! We are not being patronising when we say, ask your consultant to explain and to write them down clearly so you can research them, find out what they mean and have a better understanding of what is being talked about.



Here are some tips on how you can support them and find out how you can be supported, as well as information about the treatment pathway your loved one may experience.

Your notes

Horizontal lines for taking notes.

TIPS

- Take a notepad and pen and take notes at consultations
 - Ask the consultant to write down answers to your questions if you don't understand them at the time
 - Ask the consultant to write down any complicated words or drug names
- Ask for support literature like booklets, factsheets or pamphlets, they will be very important in informing you

Treatments

How a Treatment Plan is made

The patient's case is discussed at an MDT (multidisciplinary meeting) by the urology team which includes the surgeons, oncologists, radiologists, histopathologists, and nurses specialists. Treatment options are discussed, and treatment plan/treatment options are agreed.

Preparation for surgery

If your friend lives alone, help them plan who will take care of their children/house/pets and what alternative arrangements will be needed while they are in hospital and during recovery afterwards.

Make sure the house is in order ready for discharge home from hospital and food provisions are in place, and additional help is available until the patient can resume normal activity. If there are any issues travelling to and from the hospital, help the patient resolve them.

There may be a pre-operation appointment that the patient needs to attend so you may be asked to help with that. Help the patient pack a bag with suitable things for the stay in hospital.

If supporting the patient means you need to make alternative arrangements for yourself, this needs to be factored in.

Surgery

Radical Nephrectomy (Removing the kidney) partial Nephrectomy (removing part of the kidney with the tumour in and preserving the rest of the kidney).

Refer to the booklet "Surgery and Recovery" for more information.

Your notes

Horizontal lines for taking notes.

Hands on caring

Support following surgery and on discharge home

When first leaving hospital after the operation your partner/ family member/friend will still have discomfort – a cushion held against the wound(s) can help on the journey home, especially as the car's seat belt often crosses the wound sites. The patient may need support to get in and out of the car and the journey can cause discomfort, especially if it is quite long.

Once home the patient will need to get plenty of rest and will likely be in some pain. Getting up and down will be uncomfortable, as will lying down – many patients find it easier to sleep in a semi-upright position for the first few days/weeks, so lots of pillows will be useful.

Diet and fluids

Patients often have a lack of appetite post-surgery. Helping to encourage eating little and often/small meals. Eating fresh fruit and vegetables, wholemeal bread, and cereals to help reduce the risk of constipation. Good nutrition is vital to help with the healing process.

Encourage a good fluid intake of 2-3 litres per day (unless a fluid restriction has been advised by the medical team) as this will help look after the kidney. Water or cordials are better for the bladder and kidneys. Avoid drinking too much caffeine-based drinks (tea and coffee) and carbonated drinks as they can irritate the bladder causing an overactive bladder.

You will find more dietary advice in the information booklet "Surgery and Recovery".



Follow up post-surgery

The consultant will arrange an appointment for review in the out-patients department or by phone in about 6-8 weeks following surgery to discuss the histology/outcome of the operation.

Offering to accompany them to the hospital consultation appointments or sit with them if these are by phone. Take notes during appointments – patients’ memories can be foggy, and the amount of information they receive can be overwhelming. Taking notes can ensure they have the information they need later.

Follow ups

Ongoing follow up will depend on the cancer type, found on the histology this will be explained at the first clinic visit. Drive the patient to appointments. And when treatment is over, drive them to check-ups and scans. They may not show it, but kidney cancer patients often have a lot of anxiety about these appointments even years after treatment.

Your notes

Horizontal lines for taking notes.

Body and mind wellbeing

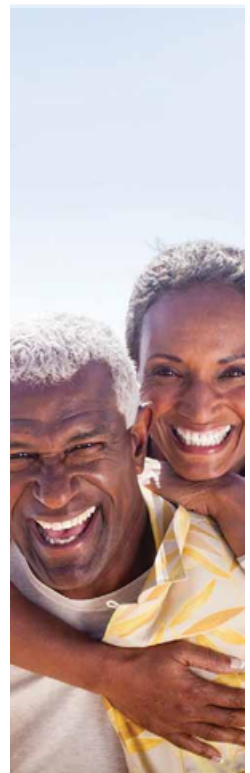
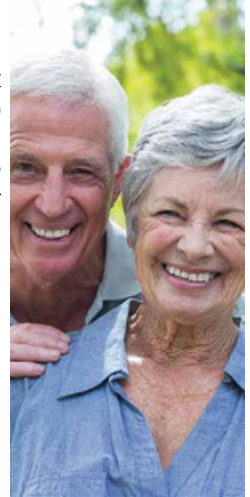
Mental health and wellbeing

It is natural to feel low in mood, tearful, frightened, and concerned at all stages of a kidney cancer diagnosis from surgery, whilst waiting for histology results too, followed by follow up scans. Allow your partner/family member/friend space, listen, and encourage them to talk. If you are concerned, please contact the patient's key worker at the hospital or contact the Support Line for advice.

Remember that most kidney cancer patients don't want to be treated differently just because they have kidney cancer. Sometimes people are so worried about upsetting a patient that they avoid them completely. Talk to your spouse, partner, family member or friend like you did before. Talk about what's going on in the community/life in general, favourite TV shows, etc. This can briefly help take their minds off kidney cancer. Encourage the wider family and friends to do so that life is as normal as possible for the patient.

Just being there for them

Just sit with them and listen. Don't offer advice or recommendations unless asked. Instead, listen to your friend's concerns, acknowledge that kidney cancer is horrible and offer a shoulder to cry on. And if they don't feel like talking, sit there with them quietly. There is a lot of power in simply being present.



Stay connected

Send texts, call, zoom, skype, email, cards, etc. So that they know you care and feel supported.

The power of music

Play music. Whether you play an instrument, make a playlist, or turn on some tunes, music can help everyone relax and help to take their minds off kidney cancer.

Art therapy sessions

Visit the website to explore and see when the next dates are scheduled.

Laughter really is good medicine

Make them laugh. Tell jokes. Share funny videos. It can be painful to laugh in the aftermath of surgery, but the benefits can often outweigh the immediate discomfort.

Relaxation techniques

Yoga (it is advisable to consult with the surgeon when this can commence post-surgery) and meditation can help.

Help to motivate

Find ways to motivate them whether that's exercising, taking medications or eating/drinking more to do what they need to do to get better following surgery or keeping their body and mind active in supporting their physical and mental wellbeing.

Your notes

Horizontal lines for taking notes.

When should you call for professional help when caring for someone at home?

Contact the palliative care team/hospice/district nurse/GP, or oncologist for help in any of the following situations:

- If showing signs of discomfort, such as by grimacing or moaning, and pain is not relieved by the prescribed dose of pain medication.
- Experiencing onset of new symptoms, such as nausea, vomiting, increasing confusion, anxiety, or restlessness.
- Experiencing other symptoms that were previously well controlled.
- Having trouble breathing and restless/upset.
- Experiencing constipation or unable to pass urine.
- If showing signs of depression or talking about suicide.
- If having difficulty giving the prescribed medicines.
- If you are feeling overwhelmed by caring for your loved one, you are feeling sad, anxious or afraid. Or you do not know how to handle a certain situation.

When is the right time to use hospice care?

Hospice care is not only appropriate in the last days or weeks of life. It can be used as much as 6-12 months before death is anticipated.

Hospice care offers many helpful services, including medical care, counselling, and respite care. The hospital oncologist/doctor/nurse specialist usually makes a referral to the palliative care team for patients that require support/symptom management and control in the community.



For you

Remember to always give yourself some time to relax

The following poem and quote were written for Kidney Cancer UK by a carer.

“A carer is classed as anyone, be it a child, friend, sister, brother, spouse who looks after a family member, friend, partner because of their health, disability, or health issues.

Carers don't often see themselves as carers, and sometimes feel that they are not providing much in the way of help, but carers are there to give support, comfort, reassurance, encouragement, and love.”

A Carer

A carer can be anyone
Any one at all
They are the person by your side
To catch you when you fall.

Your wife, your husband, daughter
You in law, neighbour, son
Your friend, your mother, your father
To them is to who you run.

A carer is someone who listens
Who will only be one step away
But that distance will diminish
To steady you if you should sway.

A carer will not always feel
That they are a carer at all
For they do the things they feel they should
Juggling all the balls.

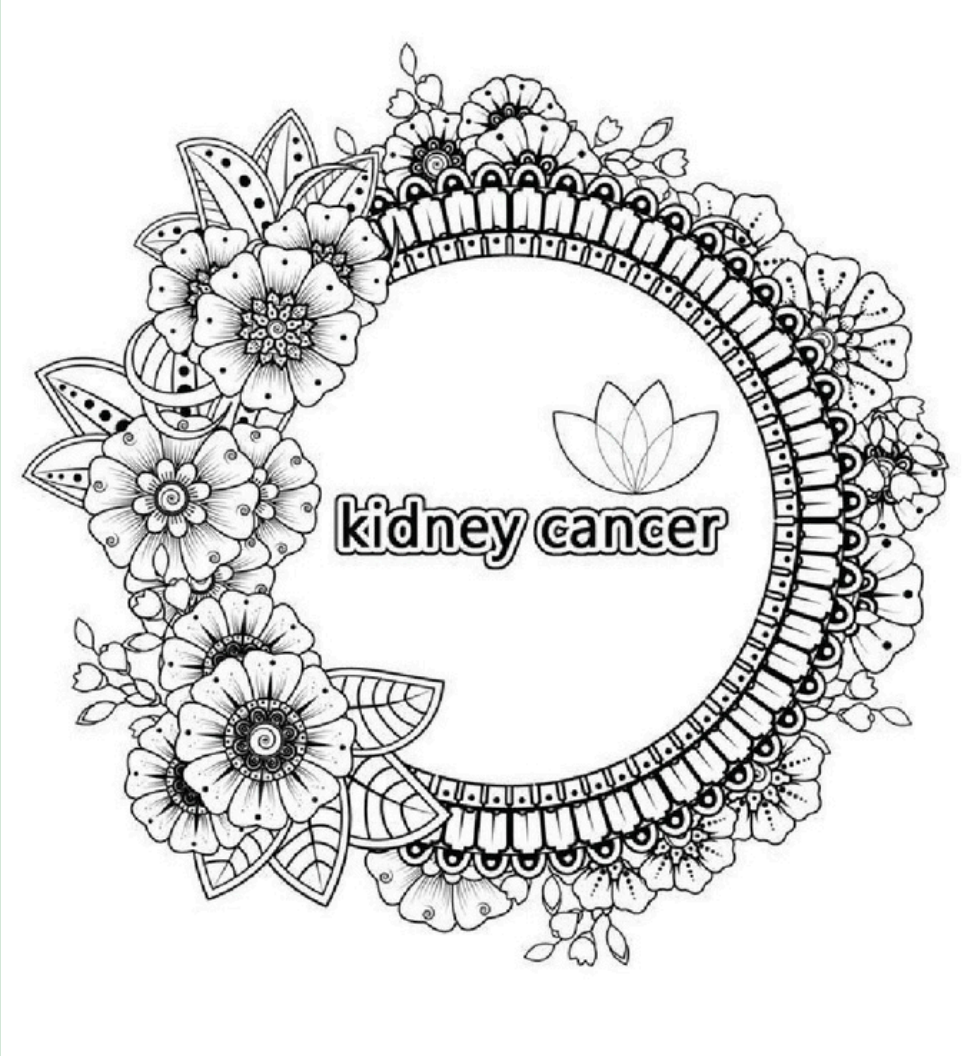
As a carer you are appreciated
For all the things you do
Every time you sit and lend you are
Every hand you clasp with two.

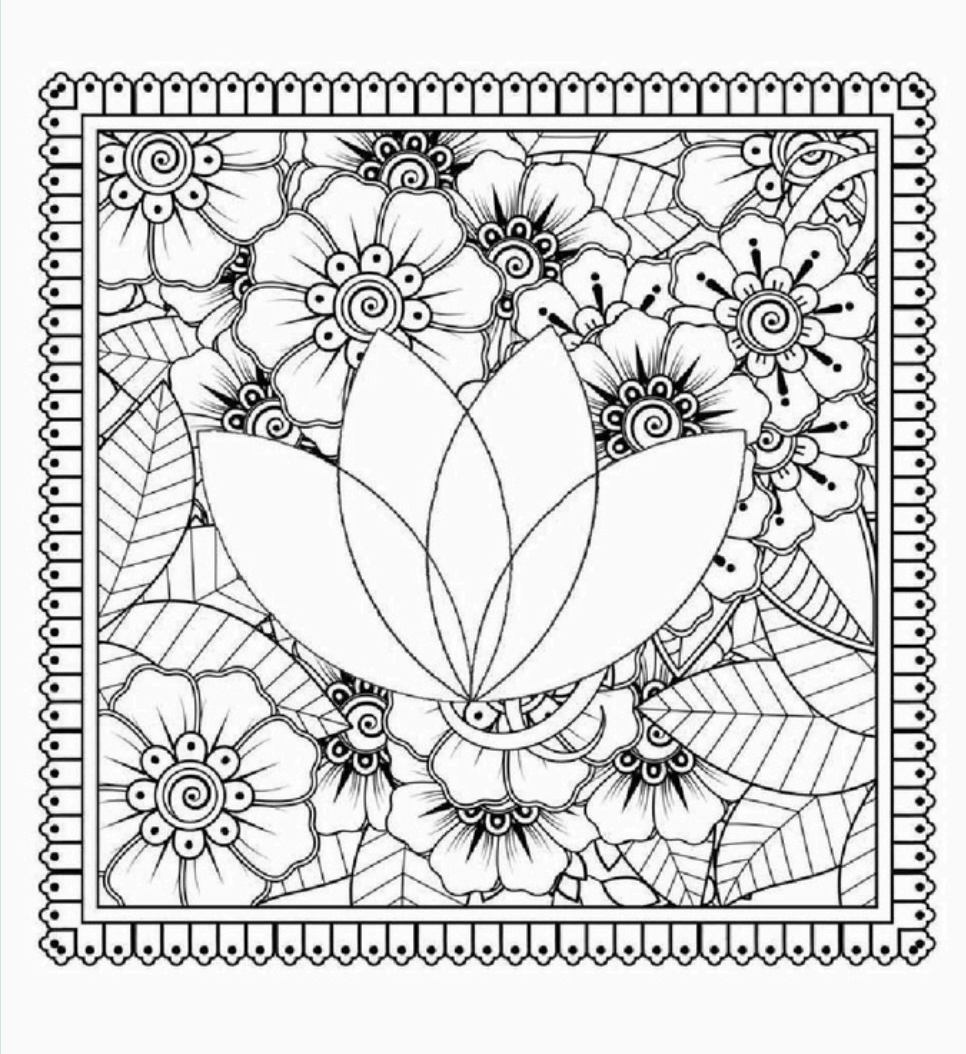
It will not always be easy
Sometimes it will be tough
But together as a unit
We can help each other through the rough.

Never forget to look after you
You are as important as they
Eat, drink, relax if you can
Tomorrow is another day.

For you

Arttherapypicturesto relax andcolouratyourleisure





For you



Here is a word search to do

P	I	E	H	B	K	K	A	W	P	U	Y	S	U	Z
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B	U	X	M	C	O	N	I	O	U	L	E	N	H	Y
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ENCOURAGEMENT COUNSELLING BENEFITS DAUGHTER CARELINE KNITTING

READING WALKING SUPPORT MEDITATION FAMILY HUSBAND MUSIC

CARERS LOVE HELP GYM SON FRIEND WIFE

Hospital appointments

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Your donation is essential 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 you or someone you know help us and make a difference?

SET UP A MONTHLY DONATION

LEAVE US A GIFT IN YOUR WILL

ORGANISE A FUNDRAISING EVENT

TAKE PART IN ONE OF OUR CAMPAIGNS

VOLUNTEER

With your generous support we can continue to invest in patient support and research. Without research, the treatment patients receive today will be the treatment they receive tomorrow.

Please visit our website for more information about how you can support our work www.kcuk.org.uk/donate or return the form 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



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