



NEW REPORT FINDS KIDNEY CANCER PATIENTS ARE BEING MISDIAGNOSED, CONFUSED & UN-INFORMED

Annual survey report from Kidney Cancer UK spotlights problematic communication gaps during kidney cancer diagnoses, and urges health professionals to be more proactive with signposting to free support services from the charity sector

- **One in four kidney cancer patients are being initially misdiagnosed – delaying their access to treatment**
- **More than a third are “unhappy” with how they were told they had kidney cancer, and over half wanted more information**
- **Only 1% of patients were given details of a support line, and just 17% were offered counselling services**
- **Lack of information and support is creating unnecessary anxiety**
- **In response, Kidney Cancer UK urges health professionals to signpost patients to free support services that are available**

Sunday 4th February, 2024: Kidney cancer is the seventh most common cancer in men and women in the UK, with 13,322 new cases annually. Around 4,700 people in the UK die each year from the condition (that’s around 13 people every day), and mortality rates have increased by 73% since the 1970s.

The earlier kidney cancer is diagnosed, the better the outcome for patients. But a new survey report* released today by [Kidney Cancer UK](#) – the UK’s leading kidney cancer charity – has found that almost one in four (23%) kidney cancer patients are being initially misdiagnosed with a range of more than 10 conditions before reaching the correct diagnosis.

Receiving a kidney cancer diagnosis is upsetting for anyone. But for the 48% of patients who are diagnosed when having a scan or test for a completely unrelated condition, it comes as an even greater shock. And of course, misdiagnosis significantly delays patients from accessing the correct, life-saving treatment that they need.

As well as shining a spotlight on the frequency of misdiagnosis, Kidney Cancer UK’s new data has also identified some concerning gaps in communication that are occurring during the kidney cancer patient diagnosis pathway – likely due to shortage of time and excessive workload facing healthcare providers and cancer units – which is creating unnecessary confusion and anxiety in patients.

According to the charity’s 2023 annual patient survey report – the only survey focused on UK kidney cancer patients – well over a third (37%) of patients are “unhappy” with how they were told they have kidney cancer, and almost a quarter (23%) believe that they should have been told in a more sensitive way.

Over half (52%) wanted more information given to them, and one in five (21%) said they were not assigned a named Clinical Nurse Specialist (CNS) at the point of diagnosis – the importance of which is emphasised by NHS England’s Service Specification for kidney cancer - calling into question whether patient choices about their treatment are being fully informed.

Further to this, only 17% of kidney cancer patients were offered counselling services on the NHS following their diagnosis, despite this being an available service. Of the respondents who did

undergo counselling, one in five (22%) said that they accessed it privately or via a charity – and well over half (55%) found it useful.

And the lack of support felt by patients seems to stretch to treatment too. According to the survey, more than a quarter (27%) of respondents who underwent surgery for kidney cancer said they “felt abandoned after surgery” and “wished there was more contact with health professionals”, with around a third (30%) saying they felt “emotionally low” or “anxious” (33%) as a result.

With budgets severely stretched for health providers, and health professionals’ time at a premium, it is challenging to provide a full range of materials and resources to support kidney cancer patients.

Thankfully reliable information resources do exist and are provided at no cost to patients. These include support lines, websites and increasingly, many secure social media support groups, from third sector organisations, including Kidney Cancer UK. However, the survey report has found that health professionals are not effectively signposting patients towards such sources.

According to the survey, only 1% of patients were given details of a support line following diagnosis, and less than 1% were given details of a website. Worryingly, 5% were given no information at all.

As a result of these findings, Kidney Cancer UK are strongly urging healthcare professionals to inform patients about free, reputable information sources they might wish to contact, including websites, telephone support lines and counselling services.

Malcolm Packer, Chief Executive Officer, Kidney Cancer UK says: *“The NHS does not have the resources to provide its own patient support and information hubs, such as dedicated cancer-specific websites and social media pages. Consequently, many kidney cancer patients say they are left feeling confused, scared, unsupported and not in control during and following treatment.”*

Kidney Cancer UK continues to be an invaluable source of information to those living with a kidney cancer diagnosis, but until communication processes are streamlined between cancer units, patients, and free services, we are doing a disservice to those living with kidney cancer – who rely on credible, clear advice and support.

Following the results of our latest survey, we are urging healthcare professionals to improve on this aspect of care urgently, by signposting patients to the free support services that are available, to ensure things are not made more difficult for patients than is necessary.”

James Whale MBE, Broadcaster and Life-time President of Kidney Cancer UK says: *“I know from personal experience that receiving reassurance and clarity from healthcare professionals can have a significant impact on how you digest and deal with a kidney cancer diagnosis, and is vital for a positive outlook.*

I hope that the communication inefficiencies highlighted within Kidney Cancer UK’s recent survey report are addressed soon, so that individuals living with kidney cancer can feel more informed, empowered and confident.”

Professor Grant Stewart, Professor of Surgical Oncology at University of Cambridge and trustee for Kidney Cancer UK says: *“Whilst these findings are no doubt symptomatic of the wider challenges being felt across our healthcare system, without a call for change, patients diagnosed with kidney cancer in the UK will continue to feel confused and anxious as a result of the lack of support information offered - stemming from a lack of signposting within some cancer units. Charities, free counselling, community groups on social media or in-person meetings, are vital services and*

resources that not nearly enough patients are currently tapping into. Improving on such signposting from the moment of diagnosis onwards will help every kidney cancer patient feel more informed, valued and supported."

For support and further information relating to kidney cancer, visit: www.kcuk.org.uk

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For further information please contact:
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Notes to editors:

****This is the ninth , and only UK-focused, annual survey of kidney cancer patients. It ran online from 23rd September 2023 to 12th November 2023 and received 610 responses, 508 of those were completed surveys from kidney cancer patients in the UK.***

About Kidney Cancer UK

For the over 20 years Kidney Cancer UK has been a consistent, prominent and influential name working to support patients through the approval of drugs for kidney cancer patients, better treatments and a clear treatment pathway. We seek to reduce the harm caused by kidney cancer by increasing knowledge and awareness, providing patient information and by supporting research into the causes, prevention, and treatment of the disease. www.kcuk.org.uk

About kidney cancer:

- In 2016-2018 there were around 13,300 new cases of kidney cancer in the UK.
- There were 4,700 kidney cancer deaths in the UK in 2017- 2019.
- There are around 13 deaths every day from kidney cancer in the UK.
- In 2015, kidney cancer was the seventh most common cancer in adults in the UK.
- Kidney cancer accounts for about 3% of all cancer deaths in the UK.
- In UK it is the 7th common cancer,
- It has been estimated that the lifetime risk of developing kidney cancer is 1 in 52 men and 1 in 87 women will be diagnosed with kidney cancer during their lifetime.
- An estimated 46,000 people are living with and beyond kidney cancer in the UK.
- 5-year survival rates in the UK are amongst the worst in Europe.