



## **PRESS RELEASE**

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### **New patient survey, by the James Whale Fund for Kidney Cancer, highlights the urgent need for improved and earlier kidney cancer diagnosis.**

A recent survey undertaken by the James Whale Fund for Kidney Cancer has highlighted the urgent need for improved and earlier diagnosis of kidney cancer: an overwhelming majority of patients – seventy percent – found out they have the cancer whilst having scans for unrelated conditions. Significantly, an early diagnosis is often the key to a successful outcome for people.

The Kidney Cancer Patient Survey 2015, which involved participants from across the UK, also highlighted the need for improved information at the time of diagnosis – a time when people are most vulnerable - as more than half the respondents were not satisfied with the information, verbal and written, that they were given:

- Over half the patients surveyed wanted more information, even though they understood everything when diagnosed.
- Just under half (forty-four percent) said they did not receive enough information about kidney cancer and the stage their illness was at.
- Lack of information about financial help and benefit entitlement was identified by forty percent of respondents.
- Eighteen percent said they did not understand everything and were confused.

Lack of information was also pertinent at the time of surgery and recovery, with twenty percent of people not content with the information supplied to them. A lack of information on drug treatments and how to manage side-effects was highlighted by five per cent of respondents.

### **Conclusion**

The survey's key findings detail that the communication people with kidney cancer receive, falls far short of exacting standards expected. People deserve to be sensitively told when they have kidney cancer, receive information that will help them cope with such life-changing news and understand what their kidney cancer journey will involve at all points.

Strong campaigners of earlier diagnosis, the James Whale Fund is adding free doctor training in 2016 to their training portfolio. The aim of this course is to raise awareness and knowledge of kidney cancer, with the aim of improving early diagnosis rates. The course, aimed at newly-qualified registrars and GP's, can contribute to their continued professional development (CPD) points.

The Fund also calls for the government to:

- Improve funding into research of a simple early diagnosis test of kidney cancer.
- Explore the viability of automatic screening for kidney cancer from 45 years of age.
- Give patients access to more life-saving and life-extending drugs across the UK; currently there is only one.
- Promote awareness that kidney cancer is a silent killer and to look for the ten signs of kidney cancer:
  1. blood in the urine
  2. persistent low back pain
  3. pain in the side, between the ribs and hipbone
  4. a lump or mass in the area of the kidneys
  5. persistent high temperature
  6. night sweats
  7. high blood pressure (hypertension)
  8. tiredness
  9. weight loss
  10. loss of appetite

Nick Turkentine, CEO of James Whale Fund for Kidney Cancer said; “The findings of our survey show an urgent need for greater awareness of the symptoms of kidney cancer. For the government, this needs to be a priority for the general public and medical practitioners. For too long kidney cancer – despite being the eighth most common cancer in the UK - has been a low priority and generally the first people hear of the disease is when they, or a loved one, are diagnosed. Cases are on the increase, 10,000 every year with just under a fifty percent survival rate”.

He concluded; “When a diagnosis is given, in addition to it being communicated in a caring and compassionate way, it needs to be accompanied with material to help the patient understand what they are being told and which contacts can support them on their journey.”

For further information on kidney cancer visit [www.jameswhalefund.org](http://www.jameswhalefund.org)

**Ends**

**For further information please contact**

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**Notes to editors:**

**THREE KEY SURVEY POINTS EXPLAINED:**

## **1 - Methods of kidney cancer diagnosis and the aim to improve early diagnosis rates**

It is not uncommon for people to be diagnosed with kidney cancer following an unrelated medical scan. The results of the survey this year illustrated this point quite clearly.

**70%** of people were diagnosed with kidney cancer while receiving a medical scan for an unrelated condition. An increase in scanning equipment and availability in the next five years was also a major topic at the 'Britain against Cancer' conference this year, which is very positive to hear and we should be fully behind steps taken to make this a reality.

**47%** of people also did *NOT* feel unwell before being diagnosed with kidney cancer. This, and the fact that a large number of kidney cancers are picked up during unrelated scans, highlight the nature of kidney cancer and the difficulties faced in its early diagnosis. Too often symptoms only show up when the kidney cancer is at an advanced stage. Symptoms are often vague and can be mistaken for other conditions.

Of the **30%** of patients who did see a GP about symptoms relating to kidney cancer, **44%** were sent to hospital on that first GP visit. We would like for the diagnosis process to be sped up, however, we are aware that GP's form a diagnosis by ruling out more common conditions, such as urinary tract infections, first and often wait for blood and urine tests which often come back negative. Kidney cancer can be very difficult to spot which is why we are calling for investment from the government in research for a standard blood test to be part of regular screening.

To try and improve early diagnosis rates we are in the process of writing an online course for GP's and newly-qualified registrars, to increase their knowledge of kidney cancer and raise their awareness. With the aim that kidney cancer symptoms will be fresh in their minds when they then meet patients. We are also looking to fund scientific research into areas aimed at developing tools to aid early diagnosis.

We are funding a research team that is looking into potential biomarkers for kidney cancer. If a kidney cancer specific biomarker was identified and could be tested for in blood tests, for example, it could easily be used in General practice medicine. In the same way PSA levels are tested and monitored for prostate cancer. People with a raised level of that particular biomarker would be fast tracked to be scanned. In the future this will hopefully become a reality

## **2 - People want more information about kidney cancer and the support available, especially when first diagnosed.**

The survey also illustrated that many people are very keen for more information about kidney cancer. At the stage of diagnosis in hospital, **40%** of people taking our survey said that they did not receive any information about self-help groups and specialist kidney cancer charities, but would have liked to.

**44%** stated that they did not receive enough information about the condition and the stage of their disease. **40%** of people would have liked more information about financial help and benefit entitlement, but did not receive any details about this.

When people were diagnosed with kidney cancer, **54%** said they understood everything, but still wanted more information. **18%** of people said they did not understand everything and were confused. All of these facts suggest that there is a very real need for information at the time of diagnosis to help people cope and understand what may happen in the future.

It is one of our aims to help provide this information, but it is clear that more time needs to be taken by the medical profession to either explain about kidney cancer and its treatment when people are diagnosed or point them in the direction of kidney cancer charities, such as James Whale Fund for Kidney Cancer. People often may need more time to process the fact that they have kidney cancer and will then have many questions at a later date. Having charity details and a telephone number for their named Clinical Nurse Specialist is vital to help people understand their situation once they are ready to ask questions. **35%** of people completing the survey were not given the name of a Clinical Nurse Specialist, a statistic that could be improved upon. We have a great tool in our 'Understanding Kidney Cancer' booklet that is available on our website but we need to make sure the medical profession are telling people that it is available.

### **3 - Improved information about surgery and aftercare is needed.**

**20%** of people completing the survey said that they were not happy with the information received about surgery and their recovery. In contrast to just **5%** of people who said they did not receive enough information about their drug treatments and how to manage side effects.

Specifically many people left individual comments about how they were surprised about how they felt after surgery and the complications of their surgery. It will be one of our aims to try and improve the level of information people are supplied with about surgery aftercare and what to expect when you have surgery. **90%** of people taking the survey had had surgery for kidney cancer, with an equal split having open surgery v's laparoscopic surgery. So, more information about this area will be valuable for a large number of people with kidney cancer.

The survey has been very useful to highlight which areas of the kidney cancer patient experience are working well and which areas need improving. The overall results of the survey will be available in the near future. Please contact us if you have any comments about areas of the patient experience that you feel need improving or that are being done well. We always look forward to hearing your views throughout the year but also look out for our next annual survey later in 2016.

#### ***About James Whale Fund for Kidney Cancer***

*James Whale Fund for Kidney Cancer is the UK's leading specialist kidney cancer charity. It seeks 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.jameswhalefund.org](http://www.jameswhalefund.org). The James Whale Fund for Kidney Cancer will change its trading name to KIDNEY CANCER UK from Monday 7 February 2016.

### **Kidney Cancer**

*Every year in the UK, over 10,000 people learn that they have kidney cancer. The incidence of kidney cancer has been steadily increasing in the UK, mainly attributed to lifestyle factors, such as obesity and smoking.*

*In addition, an increase in the number of tumours detected when a patient has a scan for an unrelated condition may have also contributed to the rise in the number of cases. Kidney cancer is now the eighth most common cancer in the UK and accounts for three per cent of all new diagnoses of cancer; it is the seventh most common type of cancer among men and tenth among women.*