



**Kidney
Cancer UK**

The UK's leading kidney cancer charity for over 20 years

Navigating the Psychological Impact of Kidney Cancer:

**A Decade of Insights into
Patient Care and Mental Health**

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Foreword

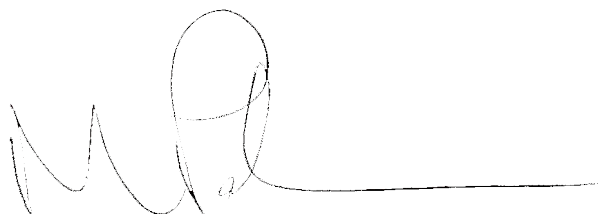
A cancer diagnosis is often more than just a medical condition; it is a life-altering event that reverberates through every aspect of a patient's existence. The immediate and long-term impacts on mental health are profound, often intensifying the physical challenges of the disease. With cancer patients facing a 20 per cent increased risk of suicide—especially within the first six months following diagnosis—it becomes clear that the psychological toll of cancer is as critical as the physical burden. Anxiety, depression, and emotional distress can significantly hinder recovery, quality of life, and even survival outcomes.

The psychological impact begins at the very moment of diagnosis. For many, the shock of being told they have cancer is a devastating blow, particularly when the diagnosis is unexpected. This is especially true in cases like kidney cancer, where nearly half of the diagnoses are incidental findings during unrelated medical investigations. The unexpected nature of such a diagnosis can exacerbate the initial emotional trauma, setting the stage for significant mental health challenges.

Understanding the unique needs of each patient is crucial. The way a patient perceives their diagnosis and the subsequent impact on their mental health is influenced by a multitude of factors, including their family and social dynamics, religious beliefs, and cultural background. These variables necessitate a personalised approach to care, where healthcare professionals must carefully consider how they communicate with and support their patients.

Research underscores the importance of addressing the emotional and social needs of cancer patients. Studies show that detailed discussions about these needs between patients and healthcare professionals can reduce depressive symptoms and foster positive psychological outcomes, such as benefit-finding. This highlights the necessity of conducting a Holistic Needs Assessment (HNA) as early as possible in the patient's journey. However, the timing of such assessments is critical; conducting an HNA too soon after diagnosis might result in incomplete or inaccurate information due to the patient's state of shock.

The findings in this document, drawn from a decade of Kidney Cancer UK Patient Surveys, emphasise the need for a nuanced approach to patient care, one that prioritizes both physical and mental health. The role of information is particularly significant to patients, who with their information needs met generally, experience better mental health outcomes. This comprehensive report provides valuable insights into how healthcare professionals and patient organisations can collaborate to meet the complex needs of kidney cancer patients, ensuring they receive the support necessary to navigate their diagnosis and treatment journey with resilience and hope.

A handwritten signature in black ink, appearing to read 'MP', followed by a long horizontal line extending to the right.

Malcolm Packer:
CEO - Kidney Cancer UK

Executive summary

More work is needed to ensure kidney cancer treatment includes an integrated package of treatment aimed at supporting the mental health and wellbeing of patients, tailored to their individual needs.

The results of Kidney Cancer UK's annual patient surveys, carried out annually over the last ten years, have guided the range of patient services offered by the Charity. This paper summarises those results to help clinics review their own support services.

Caring for patients who have kidney cancer must include support for their mental health. Providing support includes meeting the patient's individual needs for information, which can vary widely. It also includes other actions and activities that help reassure patients, and counselling services to help people who are struggling to cope.

The NHS does not have sufficient resources to provide comprehensive patient support services in kidney cancer. However, support services can be improved at minimal cost through greater collaboration with charities that have experience in counselling kidney cancer patients.

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Background

Mental health linked to a cancer diagnosis

A cancer diagnosis can have a devastating effect, not only on the physical wellness of a person, but also on their mental health and wellbeing. Cancer patients have a 20% increased risk of suicide, with the highest risk seen within the first 6 months of diagnosis.¹ In addition, recovery from cancer, quality of life and survival can be hindered by anxiety and depression.²

The impact of being told they have cancer begins at the very start of the patient's pathway, when they are told of their diagnosis. Sometimes, the shock may worse if the person is not

"it's cancer" said the Urology Consultant, and in that instant, my life changed.'

Stephen Elliott - [My kidney cancer journey - My very unwelcome guest](#) 2021

expecting to receive a cancer diagnosis, i.e. if the diagnosis is an incidental finding resulting from tests for an unrelated condition or symptoms have begun suddenly

with no warning. In kidney cancer, 48% of patients receive their diagnosis of kidney cancer as an incidental finding during a medical scan or test that was unrelated to kidney cancer.³

Understanding the patient's needs

The initial shock and anguish on receiving the diagnosis is generally only the beginning of the impact on a patient and their family's mental health. An Australian study analysing interviews with 80 patients aged between 31 and 85, diagnosed with a range of cancer types, stages and treatment trajectories, concluded that diagnosis is perceived in many different ways in addition to the initial shock.⁴ These may be influenced by the patient's family/social life, religious beliefs, ethnic background and many other factors. They are likely to have implications for the way health care professionals inform, communicate with and support the patient.

'I felt numb, shocked. In a way it's surreal. I didn't have this emotion. I couldn't cry. There were no tears. The first thing that came to my mind was: "Oh my gosh! I've got cancer; and that's one of the things that you don't want anyone to tell you.'

Jennifer Vaughan – [My kidney cancer story - F*** Cancer: A film by Rhea-Vaughan-Parry](#) 2021

A US study of 1,433 people showed that detailed discussions between patients and health care professionals about the patients' emotional and social needs were associated with a lower probability of depressive symptoms. Patients were also more likely to experience benefit-finding (a reported positive life change resulting from the struggle to cope with a challenging life event such as trauma, illness, or other negative experiences).

So, it is crucial that a Holistic Needs Assessment (HNA) is carried out as soon as possible to get to know the personal needs of the individual patient. However, depending on the patient's initial

'I just remember physically shaking from the shock and the overwhelming feeling of disbelief.'

Linzi Atkinson – ["From kidney cancer patient to top healthy eating blogger"](#) 2017

reaction to the diagnosis, carrying out an HNA immediately afterwards, though theoretically ideal, may be impractical and may capture incorrect or misleading information due to the

patient's shock. So the HNA should be carried out as soon as the patient can articulate their needs and should be reviewed regularly.

Getting to know patient needs

Although much depends on getting to know the needs of each individual patient, a great deal can be discovered through patient surveys. Kidney Cancer UK's Annual Patient Survey has been asking kidney cancer patients about their preferences for the last decade. It has influenced many of the support services we provide.

This document summarises the main learning points from the last ten years, which may be helpful in reviewing existing information and support services.

The need for information

Patient information and mental health

The role of patient information is important in maintaining mental health in cancer patients. A systematic literature review of 25 studies commented that: *'Satisfied patients, patients with fulfilled information needs, and patients who experience less information barriers, in general have a better HRQoL (health-related quality of life) and less anxiety and depression.'*¹⁵

Helping the patient understand the disease and the potential treatments, is also supporting their mental health, but how much information to provide? The level of detail needed will vary from one person to another but as kidney cancer is generally a little known and even less discussed type of cancer, we can assume that most patients have little or no knowledge about it at diagnosis. The HNA will provide a lot of clues as to the appropriate level, as well as a brief check with the patient.

The needs of each patient may change with time, so checking the HNA at each appointment is important. Selecting the right moment to give out information is equally important. The point at which the patient is told of their diagnosis may seem an ideal opportunity to give the patient a lot of information about their condition and potential future treatment. However, this is likely to be too soon for many patients as they might be too shocked to take in the details.

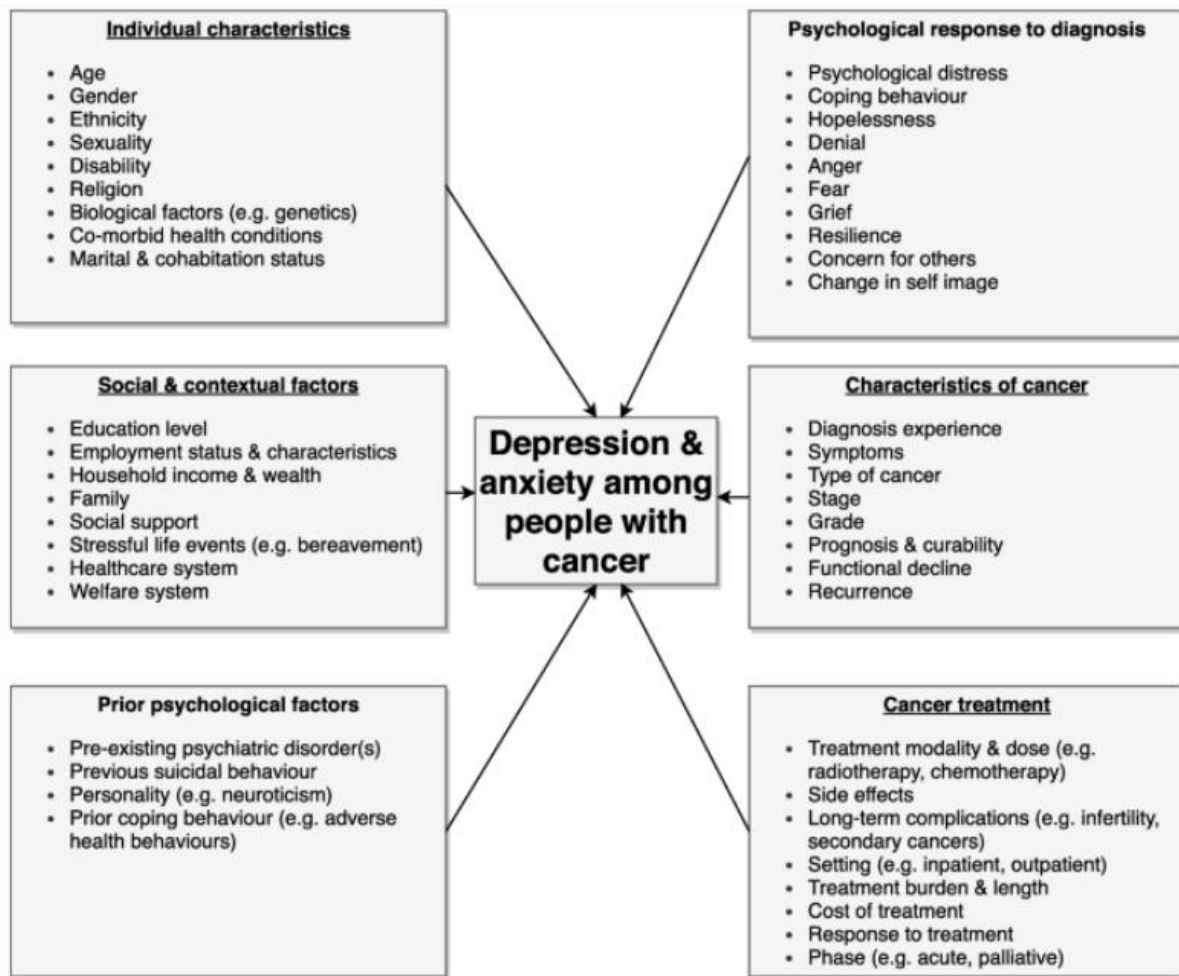
A third factor is how people want to receive the information. Some will find a conversation with the doctor and/or their clinical specialist nurse (CNS) very helpful. Others may need to go over the same information several times and may want to do so in the secure environment of their own home. Some people may want to be able to check specific points whenever they need to. Leaflets, booklets or digital information sources could be useful in both circumstances. So patient information must be available in different forms that can be tailored to each person's needs.

It is worth noting that for those patients who want to know as much information as possible, if they do not receive the level of information they want from their doctor or CNS, they may seek additional information from other sources. In these circumstances they are likely to use the internet. Unless they can be signposted to reputable sources of information, for example from patient organisations based in the UK, they might access other websites carrying information that is incorrect, out-of-date or misleading. Finding misleading information could trigger mental health issues which would not otherwise happen. Better signposting by health care professionals to online sources of reliable information for UK patients would greatly reduce such risks.

The four key questions in providing information to patients are:

- How much?
- When?
- Through which medium (verbally/ print/digitally)?
- Which are the most reputable sources?

Figure 1 Factors that may contribute to depression and anxiety among people living with and beyond cancer



(From Niedzwiedz, C.L., Knifton, L., Robb, K.A. et al. Depression and anxiety among people living with and beyond cancer: a growing clinical and research priority.²)

Providing information to kidney cancer patients

There is no reason to assume that the information needs of kidney cancer patients are substantially different from those with other types of cancer. However, this paper provides an unusually close look into the needs of kidney cancer patients over a period of ten years.

For clarity, the results are divided into two categories of information:

1. Personal information: is information specific to the patient's individual case, such as their diagnosis and their own specific test results. Personal information is only given to the

patient by their Clinical Nurse Specialist or another member of their diagnosis or treatment team.

2. General information: is information about kidney cancer that applies in general to many patients, such as what the patient should expect from different diagnostic tests, or what the results of different diagnostic tests mean in general, or what staging means. Generalised information may be given out by the patient's diagnosis or treatment team, or may be provided by other parties outside the NHS, such as patient groups.

Pre-diagnosis

Information needs begin before a diagnosis is reached. At this time some patients might be aware that there is a chance they have kidney cancer, but others might not. So, general information is best provided reactively in response to requests from the individual. Many people will not access a patient website containing information on kidney cancer (e.g. Kidney Cancer UK), and if they do, they are unlikely to be ready to process such information, as they do not have a definitive diagnosis.

However, there is a proportion of people who do want to know more at this early stage, even though their diagnosis might not be kidney cancer. This situation presents a challenge for the NHS. Information on kidney cancer comes from the relevant specialist department, but pre-diagnosis will almost certainly be too early for the patient to be referred there.

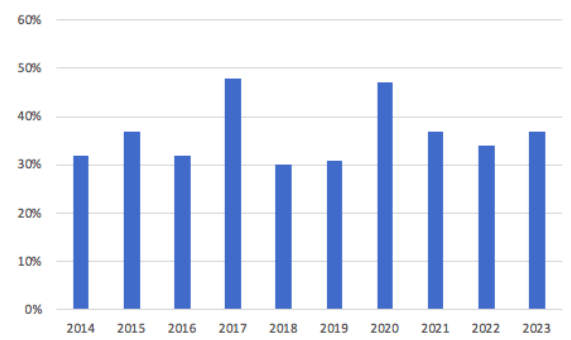
A patient organisation, even one specialising in kidney cancer, might be a useful alternative for these people. A proportion of calls to our Support Line are from people at this early stage. We are able to answer their questions about a broad range of topics, but only with generalised information (we never talk to a patient about their own specific case). However, the generalised nature of the information may be helpful because callers can explore some of the 'what ifs' that may be worrying them without the answers relating directly to them.

For obvious reasons, we have not surveyed this group of people.

Diagnosis

In our patient surveys over the last ten years, an average 37% of patients said they were unhappy with how their diagnosis was communicated to them. In addition, an average of only 36% said they were told in a way that was easily understood.

Figure 2 Proportion of patients who were unhappy with the way they were told they had cancer



The point at which the patient is told they have kidney cancer is one of the most difficult times for patients and health care professionals. The reactions to a positive diagnosis of kidney cancer are diverse, as are the needs for information at this time. The latter ranges from wanting to know everything about the disease and the treatments, to not wanting any information. We often hear patients say that if they were given a pack of written information at

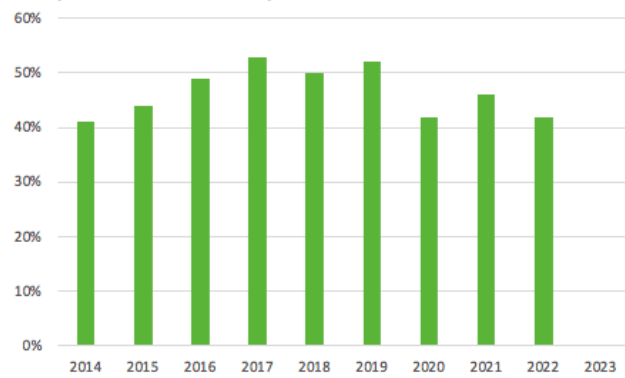
this stage, they did not open it because that made the diagnosis real to them.

Communicating personal information at this time is challenging for health care professionals in several ways:

- Conditions in the NHS mean that time with the patient is very limited.
- Yet, this is one of a relatively small number of occasions when clinician and patient are together. So it is a key opportunity to impart personal and generalised information that must be taken.
- Telling a person they have cancer is hard for health professionals. The shock to the patient may mean they take in very little of what is said to them afterwards, no matter how much time the health care professional spends with the patient.

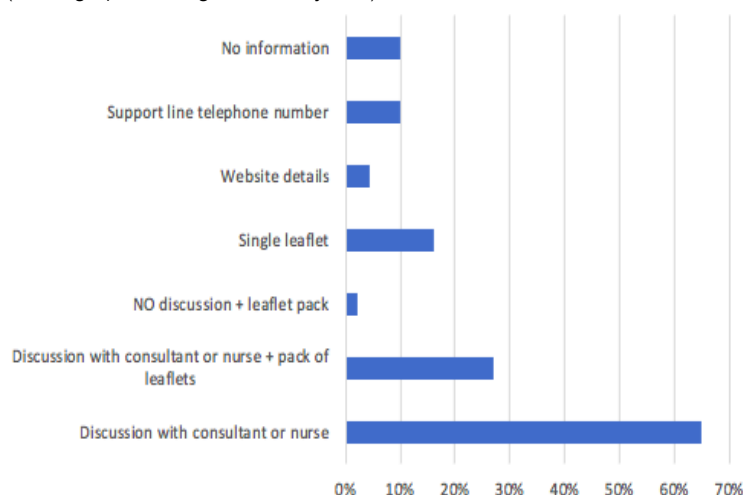
The availability and provision of general information about kidney cancer might be part of the answer to the low proportion of patients (36%) who said they were told they had cancer in a way that was easily understandable. A somewhat higher proportion – average 43% said they were told in a way that was easily understood, but wanted more information at the time. Also an average 47% said they were not given enough information at diagnosis (measured over the last seven years).

Figure 3 Proportion of patients who felt they were not given enough information at diagnosis



Between 2016 and 2021 (inclusive) we asked patients to recall the information they were given at diagnosis. An average of 65% said they had a conversation with the consultant or nurse and an average of 27% said they were also given a pack of information to take away. It is particularly concerning that an average of 10% said they were given no information at all.

Figure 4 Information provided at diagnosis as recalled by patients (Average percentage over six years)



These results strongly suggest that information and support at the point the diagnosis is communicated needs to be improved. Understandably, hospitals focus on conversations with health care professionals as this is the only way patients can be given personal information specifically about their own condition. In many cases, leaflets may be used to supplement the conversation.

Clearly, it is vital that all patients are given the opportunity to have such conversations, supported by leaflets if possible, but even this has limitations.

This has to be done during the clinic, meaning:

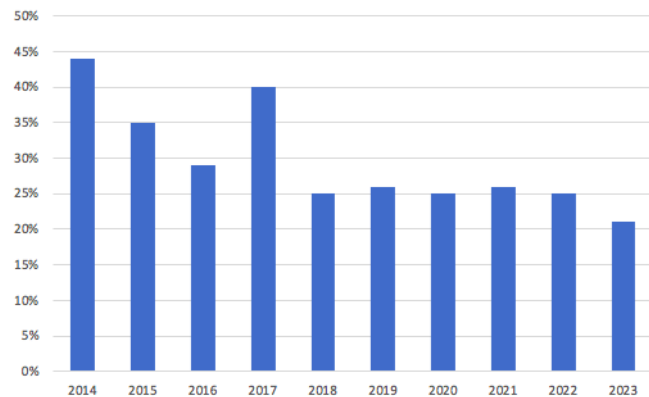
- There are significant time pressures.
- It is likely to be too soon for the patient to take in much information as they may not have recovered from the initial shock of being told they have kidney cancer.

Patients will not have had the opportunity to discuss the finding with their family, which may throw up additional questions. N.B.

Patients may be able to contact their Clinical Nurse Specialist (CNS), but we know from our survey that more than 1 in 4 patients are not given the name of a CNS. In any case, the CNS may be hard to reach due to pressure of workload. Those patients who find it difficult to self-advocate will be further excluded or missed.

The information provided at diagnosis may be comprehensive in order to cover all areas in which a patient may be interested. However, for many patients this may be too much or too little.

Figure 5 Proportion of patients who were not given the name of a clinical nurse specialist



Alternative sources of support are available such as patient organisations at this early stage could give the patient general emotional support that health care professionals struggle to find time to provide.

Treatment decisions

Over the ten-year period during which the survey was running, an average of only 11% of patients said their views were not taken into consideration when deciding on treatment, which demonstrates a positive, inclusive approach to treatment plans by NHS health care professionals. However, over the six years since 2018 we asked patients about their involvement in treatment decisions and an average of 26% said they were not given enough information about treatment.

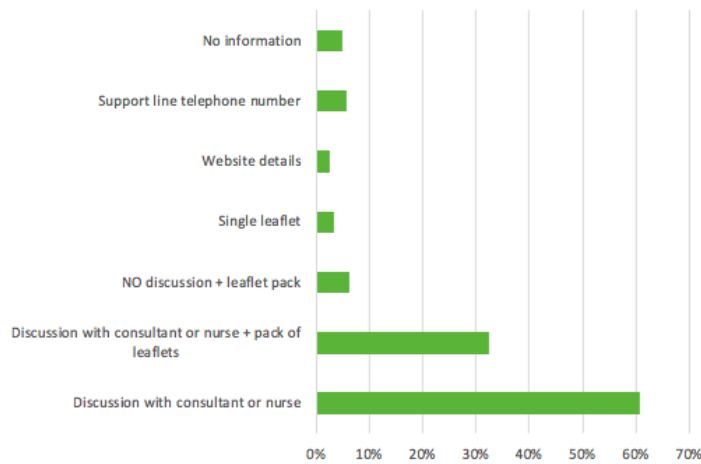
This implies that 1 in 4 patients is contributing to decisions about their treatment without having all the information they need to do so in a fully informed way.

Since 2016, we have asked patients what information they were offered about treatment. The pattern with treatment decisions is very similar to that with diagnosis.

In preparation for treatment decisions, the vast majority of patients had a discussion with a health care professional, and an average of 45% received printed information or access to information they could read at a later stage (with or without a discussion with their treatment team). Only 5% received nothing.

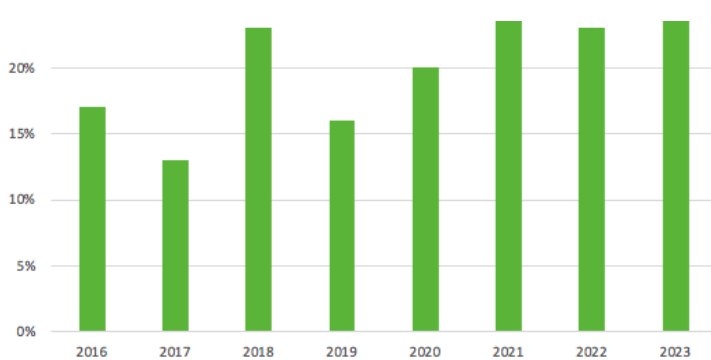
Figure 6 Information provided about treatment as recalled by patients

N.B. Average percentage measured over six years



These results suggest that the provision of information about treatment is somewhat better than at diagnosis. However, discussions with health care professionals and leaflets given out at the consultation are not supplemented by access at other times to additional general information to which patients may be directed.

Figure 7 Proportion of patients not happy with information & support before & after surgery



Over the last eight years (2016 onwards), we have compared the provision of treatment information for patients undergoing surgery with that for systemic anti-cancer therapy (SACT). Our results show that an average of 20% of patients were not happy with the information and support provided before and after surgery. With SACT and information on side-effects, a large majority, 88%, were happy with the information they received.

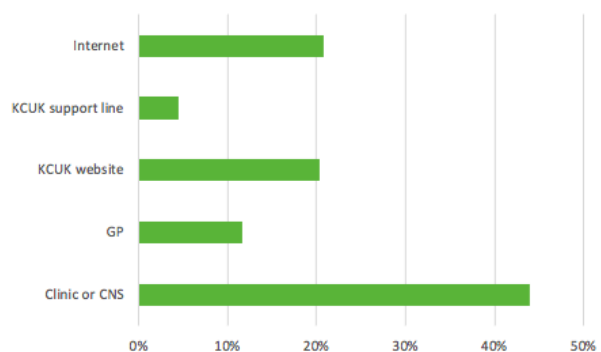
Overall, these results regarding information provided in relation to treatment decisions, suggest a better

level of provision is achieved than at diagnosis, but the drawbacks of relying heavily on conversations with health care professionals and leaflets are much the same in both cases.

Patient-accessed information

For the last seven years (with a gap in 2020), Kidney Cancer UK's annual patient survey has asked patients about the most popular sources of information on kidney cancer. An average of 44% of patients said they went to the clinic or CNS and an average of 12% to their GP. This is likely to be due to the hard work and diligence of the health care professionals working in the kidney cancer clinics and the trust and relationships they build with patients. In addition, the clinics or CNSs are the only source patients have about their own specific case.

Figure 8 Most popular patient information sources



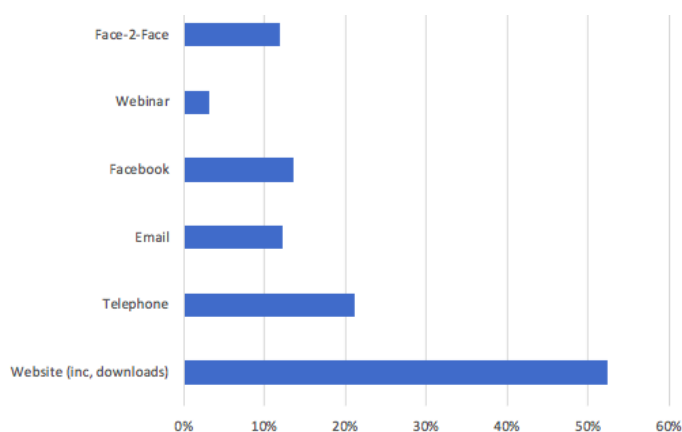
An average of 21% said they used the Internet as the next most popular source after the clinic or CNS, and a further average of 20% used the Kidney Cancer UK website. So online media are clearly popular. Since 2016 and 2017 when online sources were very high and the number one choice for patients, the proportion of people

using them has tailed off and is now very close to the median values already mentioned. It is worth noting that, whilst online information from the Kidney Cancer UK website remains the second most popular choice mentioned in our surveys, an increasing number of people communicate with us via social media.

When asked about the first point of access they would prefer to use to obtain information, a different pattern emerges. This question was asked from 2017 onwards with a break in 2020. The overwhelming favourite point of access was to go to a website (52% on average). The next most popular points of access were the telephone (average 21%), followed by Facebook (average 14%). Face-to-face contact was at an average of 12%.

One interpretation of these two sets of findings could be that whilst the clinic or CNS is regarded as the most popular source of information, websites accessed via the Internet are more likely to be used first line because they are easier to contact.

Figure 9 Patients' first point of access for information & support



The time at which people want to access information may also play a role. This was investigated in the 2016 and 2017 surveys. In 2016 the results evenly split over weekday mornings, afternoons and evenings, with a slight preference for weekends. However in 2017, 'Anytime' was added to the options and this changed the results significantly. There was a strong preference for access to information at any time.

In the same two years, patients who felt they did not have enough information at diagnosis, were asked what they would have liked to know more about. The strong preference (41% rising to 43% in 2017) was for details about patients' kidney cancer stages, types and what this meant for them.

Figure 10 Patients' preferred times to access information

Response	2016 survey	2017 survey
Weekday mornings	36%	10%
Weekday afternoons	35%	10%
Weekday evenings	38%	11%
Weekends	44%	6%
Anytime	Not included	72%

Information about a patient's own stage and type of kidney cancer and their individual prognosis is a matter for discussion only between the patient and their diagnosis/treatment team. However, there is a great deal of general information about all of these matters that patients wanting to know more might find useful; for example, by putting their own results into perspective.

So providing access to more general information about kidney cancer was a need for many patients. In fact, whilst only 7% of patients wanted more general information in 2016, in 2017 this figure rose to 20%.

Figure 11 For patients who did not receive enough information after diagnosis, type of information they would have liked

Type of information	2016 survey	2017 survey
General information about kidney cancer	7%	20%
Details about your kidney cancer stage, type and what this means	41%	43%
Treatments available for me	12%	11%
Clinical trials available to me	7%	4%
Who would be there to support me (nurses, charities, carelines, support networks)	16%	12%
Financial support information	11%	2%
Other	6%	9%

It would be interesting to repeat this question to see if these needs have changed. However, results from our most recent survey suggests this need remains. For example, many of the free-text comments made by patients in our 2023 survey mention a desire for more general information.

Summing up this section, it seems that many (though not all) patients want more information about kidney cancer, and they want to be able to access this at any time. They often look for information online, though their preferred source is the clinic or CNS. This is a trade-off between immediate access to information whenever patients need it, with access to reliable information sources and the ability to discuss their own case.

Discussing individual cases is solely the role of the clinic or CNS. However, patient organisations have an important potential role in supporting health care professionals by providing instant access to reliable information and opportunities to discuss this.

The information needs of each patient are different. Meeting those needs requires flexibility in the type, the timing and the means of delivery of information. NHS services are undoubtedly best at meeting part of the need, but resources are stretched and consequently limited in their flexibility. A collaborative approach between clinics and CNSs, and patient organisations capable of providing reliable information with the flexibility required, could open up new opportunities to meet the needs of patients.

The support needs of patients

Of course, making sure patients are informed to the extent they wish, is in itself, a means of providing support. However, most patients have other needs, which if not met, can adversely impact on mental health and ultimately on wellbeing and outcome measures. Previous trauma can resurface.

What do we mean by support?

As with information, the needs of each patient are different. It is vital that these needs are initially identified in the Holistic Needs Assessment (HNA), and equally important that they are regularly reviewed, because in most cases they will change. Many patients are not necessarily aware how they are impacted psychologically by a physical diagnosis.

Arguably and bearing in mind the variability in individual needs, major areas of patient support that help maintain the confidence of patients include:

Reassurance

One definition of successful reassurance is if a patient responds to a clinical consultation with less fear and concern about their illness.⁶ For some patients, this may be about knowing everything they need to know about their condition. For others, such knowledge could have the opposite effect; they may prefer to be reassured that they would be told if any development (good or bad) were likely to affect them ('no-news-is-good-news').

However, many other factors can be reassuring, including, but not limited to:

- Knowing everything that can be done, is being done
- Contact with other patients
- Opportunities to talk about personal feelings whenever needed
- Knowing that any concern can be raised and discussed whenever it emerges (nothing is too small or too silly)
- Knowing that the patient is not facing this on their own, (wherever that support may come from)
- Knowing that what they are going through is normal in the treatment of kidney cancer.

Reinforcement

Reassurance may need to be repeated. Particularly in the early stages of diagnosis, the shock can mean that patients are not absorbing information as they would normally do. Patients dissociate as the pre-frontal cortex isn't available to rationalise incoming information. The brain protects them in the form of denial and avoidance. Alternatively, reassurance may simply 'wear off'. So the same information may need to be communicated several times, and perhaps in different ways.

Concerns can quickly turn into worries (for example 'the question I forgot to ask'). The magnitude of kidney cancer's impact on a person's life may mean they need to be reassured from more than one source.

Normalisation (of quality of life):

Kidney cancer can never truly be normalised, but for some people accepting they need to absorb the changes resulting from their cancer into their day-to-day lives (and doing so) can bring reassurance. This can sometimes even include people dealing with late stage kidney cancer. Doubts and fear can come from any angle at any time for kidney cancer patients, but knowing that whatever the problem, they are not the first to face it can bring reassurance.

All of the above and other factors not mentioned here are all factors affecting a patient's mental health. Maintaining this, and improving it where possible, may not only improve wellbeing, but can also positively impact on clinical endpoints. It is as important as treatment of, and physical recovery from, kidney cancer.

The need for patient support in kidney cancer patients

Since 2016, Kidney Cancer UK has been asking patients how they felt following surgery. This has been a point at which the need for patient support may have been perceived by health care professionals as less important, patients mainly being monitored over many years, sometimes for life, to check if the tumour has reoccurred or cancer has spread and if it has, to ensure that treatment commences as quickly as possible. More recently, the introduction of adjuvant

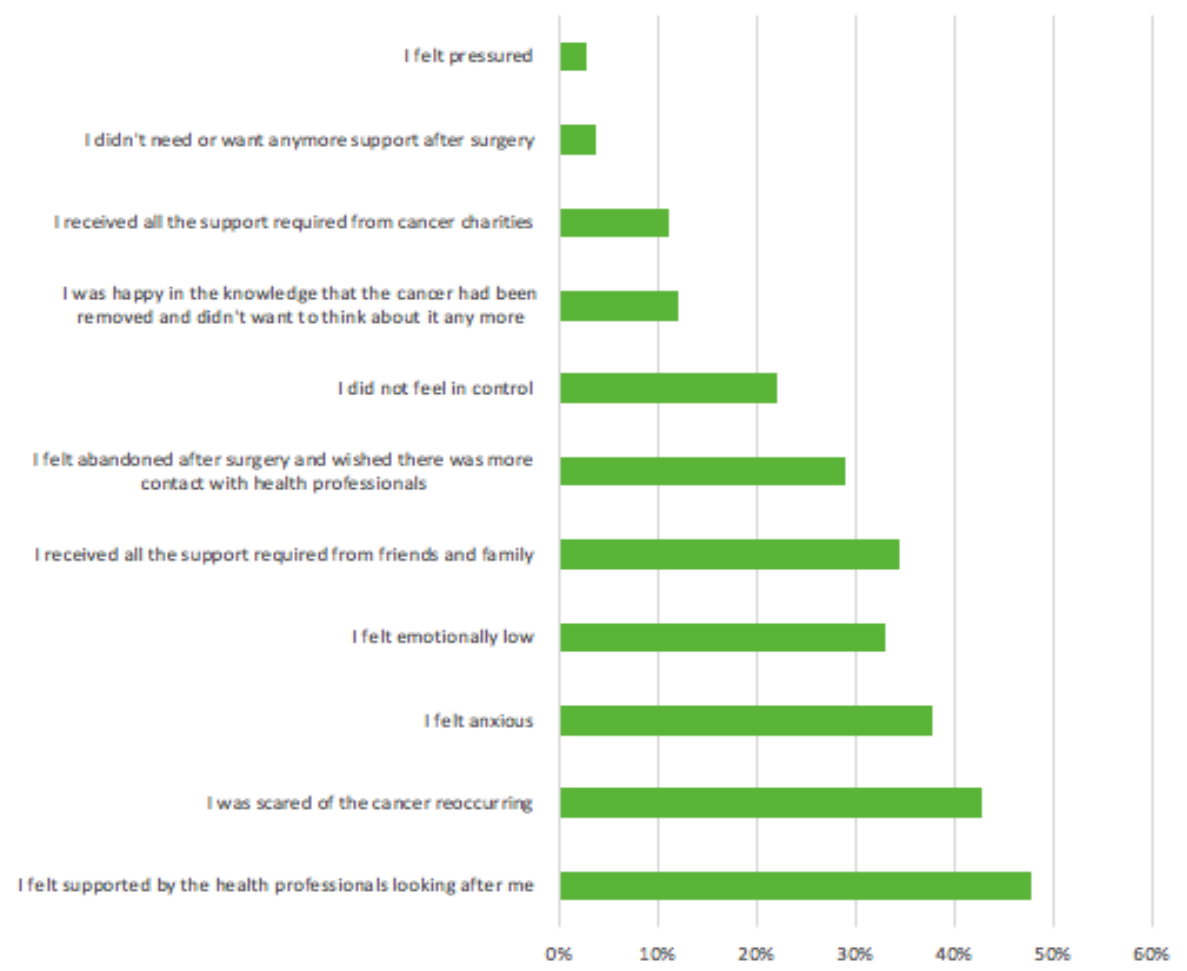
therapy might increase the need for support at this stage. Nevertheless, Kidney Cancer UK has used this metric as a surrogate indicator of the need for patient support, since it might be expected that at this stage the need had reduced or disappeared completely.

The results from the last eight years show that the above is far from reality. An average of 43% were scared the tumour would reoccur. Patients' sense of safety is often diminished or lost. An average of 29% felt abandoned after surgery and wished there was more contact with health professionals.

From 2018, further response options were added to the survey, and over the six years these continued to show a similar picture to the above. An average of 38% felt anxious, an average 33% felt emotionally low, an average 22% did not feel in control and an average of 3% felt pressured.

On the other hand, an average of 48% felt supported by the health professionals looking after them, a further average of 12% were happy in the knowledge that the cancer had been removed and didn't want to think about it anymore. 4% said they did not need or want any more support after surgery.

Figure 12 Statements describing how patients felt after surgery



This illustrates the point that patient needs for support vary, but it also shows that many patients are not being adequately supported following surgery. We do not know if this finding applies to other parts of the pathway, but there is clear evidence here of an unmet need for support.

Other data covering 10 years show that an average of 37% were unhappy with the way they were told they had cancer, and an average of 30% were not given the name of a CNS. In addition, an average of only 36% said they were told they had kidney cancer in a way which was easily understood. Though by no means conclusive, these figures suggest that patient support at other parts of the patient pathway could be improved.

Finally, anecdotal evidence from the online support group meetings that Kidney Cancer UK hold regularly suggest that patients who are about to undergo a follow up scan join the meetings because they are anxious about their forthcoming scan ('scanxiety').

Types of support for kidney cancer patients

In common with information, support needs ideally require services to be available at all times so that patients can access them whenever they need to, and as soon as they need to. In practice, this is not feasible.

Leaving aside our information services, discussed earlier, the support services we provide include:

A Support Line that is open to patients, families and carers

We operate a free telephone Support Line on 0800 002 9002 for kidney cancer patients, carers, families and friends of patients, answered by our healthcare professional team.

A suite of Facebook pages

In addition to an open Facebook page, we operate 5 closed Facebook groups. Each is focussed on a different part of the patient pathway where patients at similar stages can discuss their own experiences and concerns with other patients. One of these is specifically for health care professionals. All our pages are moderated, and our own health professionals are available to answer queries. We reach 9,000 a month on Facebook.

Other digital social media sites

We are also active on other social media sites such as X (formerly Twitter), LinkedIn, You Tube, Instagram and TikTok. In our view digital social media are rapidly becoming the most popular means of communication between patients.

Online patient groups and webinars

Some of the other services we provide via these media are regular online patient groups and events that provide the opportunity for patients to interact with national and international clinical opinion leaders through regular online webinars.

Face-to-face patient groups

Not everyone is comfortable using social media and prefer to meet other patients face-to-face. We facilitate and run several such groups including bringing our popular Living With Kidney Cancer Patient Information Days back following the Covid-19 pandemic.

Patient and Health Care Professional Blogs & Video

We have over 100 patient blogs and a wide range of exclusive videos of patient case studies and information videos from leading healthcare professionals covering a wide range of topics.

All of the above activities are aimed at reassuring patients, reinforcing information communicated to patients by their diagnosis/treatment team and dispelling myths about kidney cancer that spread all-too easily if not checked, in common with other cancers and many other conditions. Patients can also use most of these activities to help them 'normalise' their situation.

Support for advanced/metastatic kidney cancer patients

As already discussed, the needs of patients vary from one individual to another. They also vary according to the stage to which a person's kidney cancer has progressed. The support needs of patients with advanced and metastatic cancer are generally very different from those of other patients. For this reason, we provide support activities that are separate and designed specifically to meet the needs of these patients.

The important, and arguably obvious lesson we have learned is that good services must be tailored, as far as possible, to the specific needs of different patients. Failing to do this risks inadvertently disadvantaging or excluding some people, as well as reducing the effectiveness of some services.

Counselling for kidney cancer patients

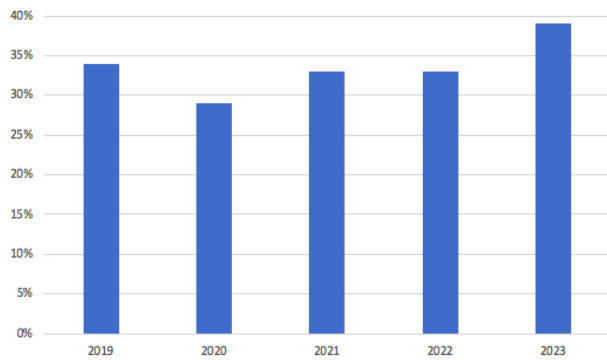
Most of our activities are aimed at helping patients maintain a good level of mental health. However, we also provide a counselling service for patients, family and carers who are finding it difficult to cope. The free service provides a course of up to 12 sessions with our trained counsellor by telephone or Zoom call, when referred by one of our nurses. We provide around 500 counselling sessions per year.

We aim to help patients understand how the diagnosis, surgery or treatment is impacting their mental health. When there is a threat to a person's existence, they may begin to re-evaluate what is important and who is important. Existential crisis brings about changes that perhaps patients would not address otherwise.

As human beings, we automatically protect our loved ones from 'seeing' our pain and fear. This creates an isolation where intrusive negative thoughts can flourish into poor mental health and adverse behaviour patterns. Having an opportunity to feel safe enough to explore these thoughts, feelings and behaviours can be enlightening and liberating.

The following data are based on patient surveys since 2019, as this is when we introduced the counselling service.

Figure 13 Proportion of patients offered counselling

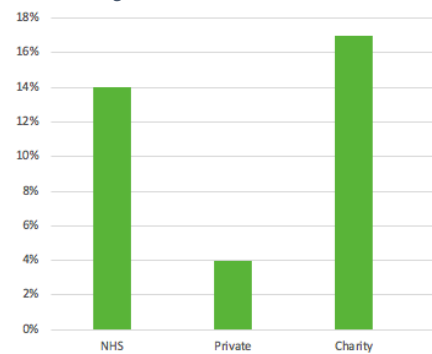


Over the last five years, an average of 34% of patients in our survey were offered counselling, but the majority were not. Of those who received counselling, an average of 54% said they found it beneficial. This suggests that access to counselling is an unmet need.

Of course, counselling is not for everyone, but in the last three years since 2021, an average of 22% of patients who were offered counselling accepted it.

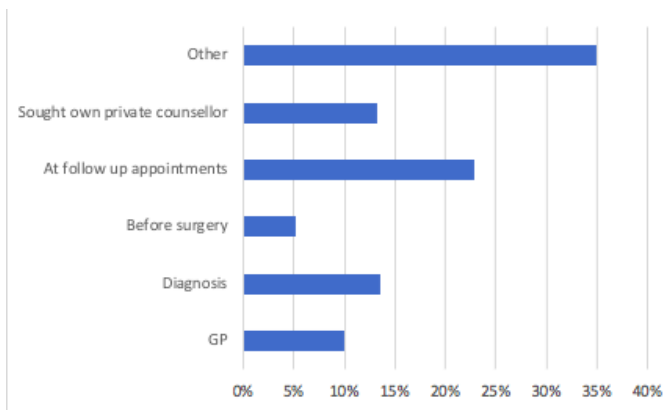
Based on data from the last three years, more people in our survey received counselling from a charity than from the NHS. An average of only 14% of people were offered counselling on the NHS, compared with an average of 17% who received theirs via a charity. In addition, a median of 4% went to a private counsellor. This is a reflection of the lack of NHS resources for counselling and mental health support relating to kidney cancer.

Figure 14 Where patients obtained counselling



Over the last five years, if counselling has been offered at all, it has happened at various points in the patient pathway, as illustrated in the graph. It is not clear whether these were the only occasions on which counselling was available or if the offer was made as a result of the patient's need at that time.

Figure 15 Point at which counselling was offered



So counselling is a valuable means of support for a sizeable proportion of patients finding it difficult to cope with kidney cancer. It should be available throughout the patient pathway and patients should be made aware that they can request counselling support at any time in the patient pathway if they feel it could be beneficial. Along with other patient support (discussed above), counselling should be an integrated part of the overall treatment package, helping patients manage their mental health

throughout a kidney cancer diagnosis. The most effective way of achieving this would be to increase and enhance mental health services available on the NHS. In the present financial situation, the NHS is unable to do so. However, this does not mean the mental health needs of kidney cancer patients should be ignored. For example closer collaboration between NHS services and charities providing mental health support for kidney cancer patients, including professional counselling, could improve access to counselling when needed.

Many patients who do take up counselling are surprised by the issues that surface from a kidney cancer diagnosis. Acknowledgement and validation of these feelings, exploring this new landscape that they now find themselves in, is beneficial to self-awareness and understanding, but many patients need to be supported as they go through this journey in addition to their kidney cancer journey.

Closing remarks

NHS services provide some support for patients, within the limitations of its resources, but for many patients, this is not sufficient. Therefore kidney cancer patient support remains an unmet need. According to our patient surveys, this has been the case for many years and there is little sign of any change⁷. NHS services need to be improved to meet this need. In addition collaborating with patient organisations that have experience in counselling kidney cancer patients could improve the situation and clinics should explore this option further.

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