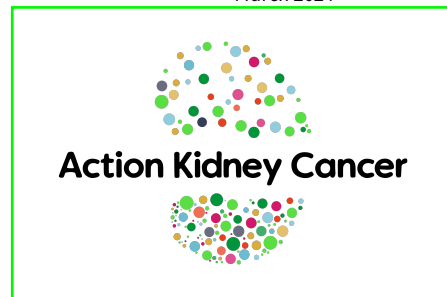
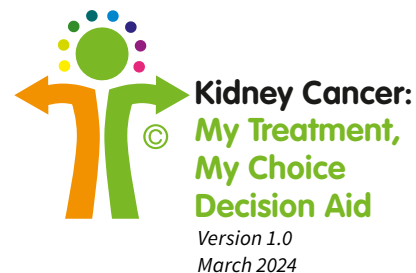


# My Treatment, My Choice

A decision aid to help people with kidney cancer (renal cell carcinoma) decide what supportive care they may need



Supporting you in the shared decision-making process with your healthcare team



[www.actionkidneycancer.org](http://www.actionkidneycancer.org)  
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**This workbook belongs to:**

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**Disclaimer**

This decision aid is intended for patients to use alongside the advice of their healthcare team. It does not support any course of treatment over another. Use of this decision aid is voluntary.

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**My Treatment, My Choice  
Supportive Care Decision Aid**

*Insert your organisation logo, address, and contacts here*



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*Perhaps you are reading this because you would like to know more about supportive care and the healthcare services available to you, or someone you care about. We understand that the medical language and the information about healthcare can be overwhelming. One of the strongest beliefs of the International Kidney Cancer Coalition (IKCC) is that patients and their families have an essential role to play in healthcare decision-making that affects their lives.*

*There are more than 430,000 people diagnosed with kidney cancer globally each year, and the numbers are increasing. People living with cancer need support to help them with the physical and psychological effects of the disease and treatments. During the past two decades, there have been many new discoveries in the treatment of kidney cancer. People are now living longer with this disease and need care and support from diagnosis through treatment and beyond.*

*The discovery of new kidney cancer treatments, the growing and aging population, better cancer survival and increasing costs of care, has led to a need for supportive care services throughout the whole kidney cancer pathway.*

**Supportive care is defined as ‘the prevention and management of the adverse effects of cancer and its treatment’** ([Multinational Association of Supportive Care in Cancer](#))

*This involves the whole cancer journey, and many clinical specialities. Supportive care is needed for the management of a diagnosis of cancer, management of treatment, and improvement of quality and quantity of life for people living with kidney cancer. This decision aid describes the various types of supportive care and builds awareness of the supportive care services that are available in most countries. This information can be used to make decisions about the support you or your loved one might need during your cancer journey.*

*This decision aid was written by a collaborative team of patients, patient advocates and healthcare professionals who have supported thousands of kidney cancer patients worldwide.*

*You may find that this booklet contains a lot of medical information and new terms. If you find it difficult to read all at once, it might be helpful to read it in sections or re-read it again at another time. For more information, and to help you understand the medical terms that are used, please also read [My Treatment, My Choice Kidney Cancer Basics](#) booklet, and/or see the glossary on page 65 of this booklet.*

*We hope that you find this booklet helpful, and it will help you with your decisions about supportive care.*

*Sincerely*



**Dr. Michael A.S. Jewett,  
Chair, International Kidney Cancer Coalition  
[www.ikcc.org](http://www.ikcc.org)**

# About this decision aid

This decision aid is for people diagnosed with a type of kidney cancer called renal cell carcinoma (RCC), including all subtypes of RCC (for example, clear cell, papillary, chromophobe and collecting duct RCC). It is for people who would like to know more about the supportive care services that might be available to them and their families and carers, and to help them decide which are the best options for them.

Access to supportive care services varies around the world. It depends on the country where you live, your national healthcare system or your health insurance. In some countries there are well established supportive care services available in cancer centres, hospitals, and hospices, and specialist supportive care doctors and nurses. However, in other countries, there are very few services or specialists, and people may need to look for services in the community. You will need to remember this when deciding what supportive care you may need.

For more information about kidney cancer treatments such as surgery and cancer medicines, please see the decision aids on the [IKCC website](#). You can also find a list of [patient support organisations on the IKCC website](#) who will be able to give you advice on the supportive care services available in your country.

## **This decision aid:**

- Explains what supportive care is.
- Provides information about the various types of supportive care services that may be available for you.
- Provides information about the possible benefits and risks of supportive care.
- Gives guidance about how to make the best possible decisions in keeping with your own values and beliefs.
- Suggests some questions you may want to ask your doctor or healthcare professional to help you decide which type of supportive care may be best for you.
- Provides lists of resources where you can find support and further information if you need it.

Having kidney cancer can be overwhelming. Learning about the disease and treatment options can help you make the best decisions about the care and treatments available to you. This decision aid also describes the things you need to think about when deciding what type of supportive care you need. It will help you with your conversations with your doctors and nurses. You are the most important person involved in your own healthcare. Only you understand the impact of these decisions on your life.



You can print out this booklet and have it with you at your next appointment with your doctor or healthcare professional. We hope you will also find this booklet useful when discussing supportive care options with your family members and carers.

**This booklet should be read together with the [My Treatment, My Choice Kidney Cancer Basics](#) booklet.**





What is supportive care?



# What is supportive care?

Supportive care is defined as ‘the prevention and management of the adverse effects of cancer and its treatment’ ([Multinational Association of Supportive Care in Cancer](#)).

There are many different types of supportive care which can help patients manage both the symptoms of kidney cancer and the side effects of surgery, cancer medicines, or radiotherapy. Supportive care is made up of a range of specialist healthcare services, such as psychological support, palliative care, counselling, end of life and spiritual care. Supportive care can provide access to physiotherapy and occupational support, diet and nutritional advice, and complementary therapies to improve general wellbeing, such as meditation, music therapy and massage.

Supportive care should be available to patients throughout the entire cancer journey from initial diagnosis of cancer through cancer treatment and beyond. It may involve you meeting many specialist healthcare professionals who work in your hospital, or in the community, or in private healthcare companies.

Supportive care is needed for the management of both physical and psychological wellbeing. The overall aim of supportive care is to improve both the quality and quantity of life for people living with kidney cancer.

## **These are some of the different types of supportive care that may be available for you:**

1. Provision of kidney cancer information
2. Self-help and peer support
3. Controlling the symptoms of kidney cancer, especially pain
4. Management of treatment side effects
5. Co-ordinated care for patients with existing illnesses or disabilities
6. Management of psychological and emotional needs
7. Diet and nutrition
8. Palliative Care
9. Social care and support
10. End-of-life care
11. Support for family members and carers
12. Rehabilitation (physiotherapy and exercise)
13. Complementary and alternative therapies
14. Spiritual support
15. Financial and employment advice/support.

Supportive care helps with the care of cancer patients following diagnosis, during treatment and into the future. Whole person (or holistic) care and improving quality of life include physical and psychosocial support, spiritual support, and complementary therapies to improve the wellbeing of patients, their family members, and carers. The principles of supportive care are:

- Supportive care aims to maintain (and, where possible, improve) quality of life, and to ensure that people with cancer can have maximum benefit from their cancer treatment.
- Supportive care is suitable throughout the kidney cancer pathway from diagnosis through treatment and beyond (including living with cancer, management of side effects, cancer survival, and end-of-life care).
- Supportive care involves a coordinated, person-centred, whole person (holistic) approach, which should be guided by the person's needs and preferences and should include support of their family members and carers.
- Supportive care is a basic right for all people with cancer, regardless of their personal circumstances, their type of cancer, their stage of cancer, or their cancer treatment. It should be available in many cancer centres, hospitals and hospices that care for people with cancer.

In some countries, supportive care may be offered outside the hospital in the community, for example, in your own home, or a care home, community hospital or hospice. You can find excellent supportive care teams in a hospice where you can be treated as an in-patient or day patient. Some countries also have community palliative care services if a patient decides to stay at home. Your family doctor or hospital team may be able to arrange for your care to be provided at home.

Supportive care should be made available to people with cancer and their families throughout the kidney cancer pathway, and should be equal to other aspects of care.



# Types of supportive care

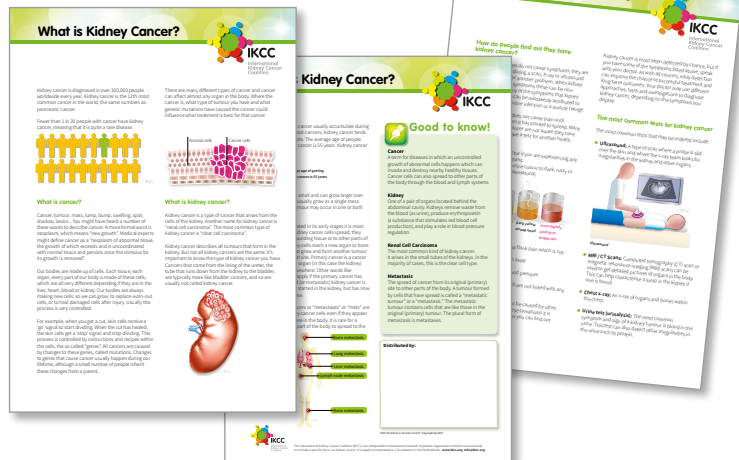
## 1. Provision of kidney cancer information

You and your family members and carers should have access to a range of information materials about kidney cancer and cancer services throughout the course of your illness. This information should be high quality, up to date, evidence-based, accurate, culturally sensitive, specific to the availability of local services, free, and accessible for you and your family members and carers.

You will need information to help you make treatment decisions and to cope with your physical and psychological needs. Good sources of information can help reduce worry and stress and help you cope with your disease. Family members and carers can also be given all the information about the treatment, side effects, plans for your care and treatment, and what to expect over time.

It is well known that people do not retain everything that is said to them at clinic appointments. You may not be familiar with the language or the medical terms, so it is not surprising that you and your family members and carers might feel very confused. It is essential that you are given written information of the highest quality that is individually tailored to your needs.

Most kidney cancer charities, patient support organisations and general cancer charities have information about kidney cancer on their websites, which can be downloaded and printed. Some also provide printed materials on request. Some specialist kidney cancer charities supply printed materials for hospital clinics to hand out to patients in their region or country. Some general cancer charities have information hubs in hospitals where printed materials can be collected by patients when they visit for their appointments.

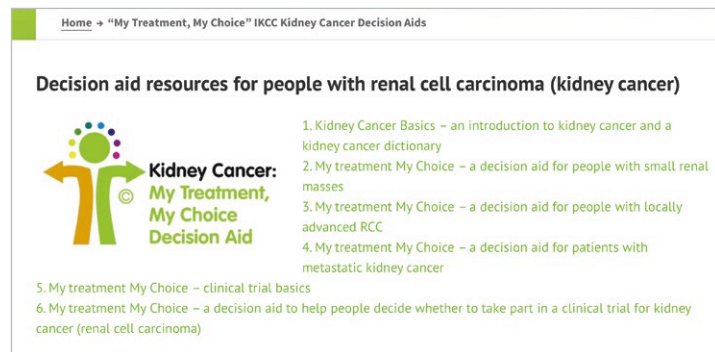


National health services and government health bodies also provide kidney cancer patient information. For example, information about the risk factors, symptoms, diagnosis, and treatment of kidney cancer on their websites. Some also provide links to national patient support organisations for further information and support services.

Many people use the internet to look for information about their cancer diagnosis, treatment options, side effects to treatments, and complementary and alternative therapies. Some people find the information on the internet difficult to understand, and it may be unreliable or not up to date. The internet is useful for finding patient support groups where you can get support from other kidney cancer patients who understand what it is like to live with this disease. Patient support groups can also be used to share ideas and information with other patients.


It is important that you are involved in all the decisions about your own healthcare. This is called ‘shared decision making’. Shared decision making is a process which makes sure patients, their families, and carers are supported to make decisions about their care and treatment which are right for them. It is a collaborative process, and it starts with

a conversation with your cancer doctor or nurse. This will help you and your family members or carers to work together with your healthcare team to make the best possible decisions for your care and treatment. It brings together the healthcare team’s expertise, treatment options, evidence, risks and benefits, and the patient’s individual preferences, personal circumstances, goals, values, and beliefs. The IKCC have produced a number of [\*My Treatment, My Choice decision aids\*](#) to help you when making these important decisions about your care and treatment.



Home → "My Treatment, My Choice" IKCC Kidney Cancer Decision Aids

### Decision aid resources for people with renal cell carcinoma (kidney cancer)



**Kidney Cancer:  
My Treatment,  
My Choice  
Decision Aid**

1. Kidney Cancer Basics – an introduction to kidney cancer and a kidney cancer dictionary
2. My treatment My Choice – a decision aid for people with small renal masses
3. My treatment My Choice – a decision aid for people with locally advanced RCC
4. My treatment My Choice – a decision aid for patients with metastatic kidney cancer
5. My treatment My Choice – clinical trial basics
6. My treatment My Choice – a decision aid to help people decide whether to take part in a clinical trial for kidney cancer (renal cell carcinoma)

# Types of supportive care

## 2. Self-help and peer support

The term self-help is used to describe everything that you and your family can do to help manage your own cancer symptoms, including finding out more about treatments, lifestyle changes, looking after your mental health, and the social, cultural, and spiritual effects of your cancer. Self-help is ongoing and should be supported by your healthcare team, especially your cancer nurse.

Over the past decade, improvements in treatments have resulted in kidney cancer patients living longer on treatment. Because of this and the rise in the number of kidney cancer patients being diagnosed, self-help is becoming more important.



There are several tools that can help patients manage their cancer. These include:

- Pain monitoring using a mobile device.
- Online remote nursing support.
- Written and visual self-help plans and diaries can be used to reduce pain, depression, tiredness and improve wellbeing and quality of life.

These tools are available online to help patients, family members, and carers access self-help support.

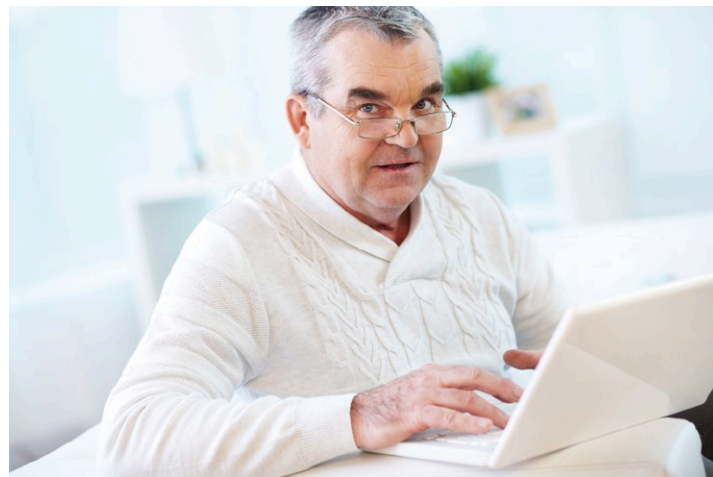
Some people are willing to use self-help to learn about their cancer care and to have some control over their lives. Electronic tools can improve self-help and access to self-help support.

You will need to discuss self help and support with your healthcare team, family members and carers to decide if this is an option for you.



You can also receive support throughout your kidney cancer journey from patient support groups or organisations, as well as sharing experiences with other patients (called peer support). Many patient support groups have online chat forums to allow people to share their experiences, talk about their feelings and get support from other kidney cancer patients, carers, or survivors who understand how you feel. Some patient support groups meet face-to-face as small groups of patients who come together to share their experiences and support one another. These groups may be organised by hospitals, where they are led by a specialist cancer nurse, or charities/patient support organisations.

Support groups can have a positive effect on those who take part. Such as improvement in mood, acceptance of the disease, and better pain control. Support groups can help people to share their feelings, make friends, learn how to cope, and live with the diagnosis of kidney cancer, as well as receive good quality, up-to-date, evidence-based information about the disease.



# Types of supportive care

## 3. Controlling the symptoms of kidney cancer, especially pain

Controlling the symptoms of kidney cancer can help to improve your quality of life, and the life of your family members and carers. This can involve controlling pain and other symptoms, for example nausea, vomiting, constipation, and breathlessness.

Pain might be experienced because of the kidney cancer itself or as a side effect to surgery. Pain relief (analgesia) has a large part to play in the treatment of pain. Common treatments are co-codamol, diclofenac sodium, paracetamol and opioids, such as morphine, oxycodone or fentanyl patches.

Different treatments are used for different types of pain. For example, paracetamol is used for the treatment of mild–moderate pain and to bring down a high temperature. Non-steroidal anti-inflammatories (NSAIDs) such as ibuprofen, are used for the treatment of mild-moderate pain due to inflammation and to bring down a high temperature. Selective serotonin reuptake inhibitors (SSRIs), for example duloxetine as well as medicines like gabapentin and pregabalin, are used for the treatment of nerve pain (neuropathic pain).

You should avoid taking non-steroidal anti-inflammatories (NSAIDs) if you have poor kidney function. Pain relief may be supplemented or, in some cases, replaced by complementary therapies, such as meditation and relaxation.

Radiotherapy is sometimes used to help control the symptoms of advanced kidney cancer. It can be used to help relieve bone pain or to treat cancer that has spread to the brain. Radiotherapy can be used to shrink tumours to reduce pressure on nerves and other organs to help control the pain and discomfort caused by compression of internal organs.

Feeling sick (nausea) and vomiting may have several causes, including radiotherapy, tumour growth, anti-cancer medication or worry about the disease. You could try eating smaller meals more often, drinking smaller amounts more often, and relaxation therapies. If these are not effective, medication to treat nausea and vomiting can be used.

Feeling extremely tired (fatigue) is one of the most distressing symptoms of cancer and can significantly affect your life. Fatigue may be caused by many things, such as

depression, trouble sleeping (insomnia), low red blood cells (anaemia), the effects of cancer treatments, and problems with your energy caused by the cancer. If you have fatigue, you might be advised to pace your activities to save your energy. Organising your home and work in a way to help you cope with less energy can help. Regular, gentle exercise and a healthy diet will help reduce fatigue, and treatment for anaemia may also help. You should try relaxing activities, such as reading, listening to music, watching TV, and a short sleep during the day.

It is not unusual for cancer patients to become constipated because of pain medications, anti-sickness medications, cancer treatment, lack of exercise, and poor nutrition. In many cases, changing your diet to a high fibre diet and increasing your intake of water can help relieve constipation. If this is not successful, you might need to take laxatives.

You might feel breathless because of fear and worry about your cancer or because your cancer has spread to your lungs. Breathlessness is also affected by the way you breathe, your lifestyle and how you think and feel about your breathing. Worrying can make you feel breathless. This could perhaps make you feel panicky and bring on

physical symptoms such as a tight chest or fast breathing. There are various breathing methods that can help you with breathlessness, for example taking slower, deeper breaths from your tummy can help ease breathlessness. If you feel breathless, it is important to talk to your doctor or healthcare team as soon as possible. Breathlessness might be a symptom of several conditions, such as a chest infection, a blood clot in your lung (pulmonary thrombosis), spread of the cancer to your lung (lung metastases), and other non-cancer related conditions.

If you need help controlling the symptoms of your cancer, especially pain, talk to your healthcare team about your symptoms and the help and support you need to manage them. You might need to see a specialist doctor or nurse to help you manage these symptoms, such as a palliative care doctor or nurse to help you manage pain, or a dietitian for constipation, nausea, or vomiting.

If you have other conditions, such as heart disease or lung disease, you might need to see a doctor specialising in these conditions to support you during your cancer journey (see section 5. Coordinated care for patients with existing illnesses or disabilities).

# Types of supportive care

## 4. Management of treatment side effects

Supportive care helps cancer patients manage their treatment experiences to improve quality of life. Treatment includes surgery, anti-cancer medication and radiotherapy.

### Surgery

Surgery to remove a kidney (or part of a kidney) is called nephrectomy (or partial nephrectomy). All surgery has some risks and complications. Possible complications of nephrectomy include:

- Infection (your surgery wound becomes painful, red or swollen, leaks fluid or has an unpleasant smell).
- Bleeding (haemorrhage).
- Post-operative pneumonia.
- Rare allergic reactions to anaesthesia.
- A small risk of kidney failure if your remaining kidney is not working properly or you have kidney disease.
- Constipation.
- Post-operative flank hernia.

If you have any of these complications, your healthcare team will manage them to make sure you recover fully from your surgery. For example, it is important that you keep your wound dry to avoid infection. If your wound becomes infected, you need to tell your healthcare team immediately.

They will clean it and dress it and give you some antibiotics.

It is not unusual for cancer patients to become constipated because of pain medications and lack of exercise after surgery. Changing your diet to a high fibre diet and increasing your intake of water can help relieve constipation. If this is not successful, you might need to take laxatives.

Excessive bleeding (haemorrhage) might occur immediately after surgery. Your surgeon will stop the bleeding and, depending on the amount of bleeding, you might need to have a blood transfusion.

Some patients develop a bulge (hernia) at the site of their wound. Hernias are sometimes monitored and do not always need repairing. However, some hernias can cause serious problems. The only way to repair a hernia is to have more surgery. Your healthcare team will be able to give you advice about the management of a hernia.

For more information about recovery after surgery, please see section 12. Rehabilitation (physiotherapy and exercise).

## Anti-cancer medication

When you are given medication for your kidney cancer, you might have some side effects. The side effects to some medications are well known and can be managed by you and your healthcare team, especially your cancer nurse. The sooner side effects are reported to your healthcare team, the easier they are to treat and manage so they do not affect your life. You should be made aware of the common side effects to kidney cancer treatments so that you can start to manage them at home. Effective management of side effects improves tolerance to treatments and increases the benefits of treatment.

The [Multinational Association of Supportive Care](#) in Cancer has developed specific guidelines for the management of side effects to treatment, such as nausea and vomiting, cancer pain, bone damage caused by cancer treatments, immune-related side effects, sore mouth, hand-foot syndrome, and palliative care. These guidelines help manage the common side effects of kidney cancer treatment and improve the quality of life of patients and their families and carers so that cancer treatment can be continued.



# Types of supportive care

## 4. Management of treatment side effects

Common side effects and how they are managed include the following:

Side effect	Management
High blood pressure	Understand what is normal for you, monitor for high blood pressure, record your blood pressure daily, stop smoking, reduce the amount of caffeine, salt, saturated fats and sugar in your diet, exercise regularly, see your hospital team or GP to treat high blood pressure with anti-hypertensive medication, if needed.
Diarrhoea	If you have diarrhoea, please let your healthcare team know as soon as possible. It is important to understand your bowel movement habits, change your diet (small, regular meals, drink plenty of water, use probiotics, increase consumption of bananas, rice, chocolate, bread, reduce consumption of high fibre food, beans, and seeds), see your hospital team or GP to prescribe diarrhoea medication, if needed.
Skin rashes	Check your skin daily, use emollient-based creams for a mild to moderate rash, e.g., zinc oxide or lanolin-based emollients, oatmeal lotion or steroid cream, wear protective clothing, use oral prednisolone for moderate to severe rash, see your hospital team or GP to or a dermatologist if the rash continues. Steroid cream or prednisolone should only be taken if prescribed by your healthcare team.
Sore mouth (stomatitis)	Keep your teeth and mouth clean, make sure you don't irritate your mouth, avoid spicy food, acidic food, like lemons, crunchy food, smoking, and alcohol, eat soft food cut into small pieces, use straws to drink through, avoid oral rinses with alcohol. See your hospital team or GP to prescribe medications or nutritional support if eating or loss of appetite becomes a problem.

Side effect	Management
<b>Extreme tiredness (fatigue)</b>	Understand the cause of your fatigue and rule out any other conditions that may be causing fatigue, pace your activities to save your energy, organise your home and work in a way to help you cope with less energy, take regular, gentle exercise and a healthy diet, relaxing activities, such as reading, listening to music, watching TV, and a short sleep during the day, relaxation techniques, such as meditation, yoga, and massage, have a regular sleep pattern, eat and drink well.
<b>Reduced appetite/ weight loss</b>	Try to eat nutritious, high-calorie, high protein foods, like eggs, fish, cheese, and meat, don't eat food that causes you to have diarrhoea, keep your teeth and mouth clean, avoid fad diets, see your hospital team, family doctor, or a dietitian if you continue to lose weight or can't eat.
<b>Nausea and vomiting</b>	Eat small meals regularly each day, drink plenty of water, eat bland, easy to digest food, such as sugar-free mints or sweets, keep your teeth and mouth clean, avoid too hot or too cold food and drink, chocolate, caffeine, alcohol, smoking, and strong smells, try relaxation therapies. See your hospital team or GP for medication to treat nausea and vomiting, if needed.

With the developments of new treatments for kidney cancer, such as immunotherapy, supportive care for the management of side effects continues to develop. Immunotherapy can cause immune-related side effects. Most immune-related side effects are not long-lasting and will settle in time. They can affect many parts of the body. The most common ones are: skin rash, gut problems like colitis, fatigue, and joint pain. The only long-lasting side

effects are those affecting the glands: thyroid (hypothyroidism), pancreas (diabetes), adrenal (adrenal insufficiency), and pituitary (hypophysitis). These side effects may be made worse using combinations of anti-cancer medications for advanced kidney cancer. Most immune-related side effects can be managed either with simple monitoring or with medication that suppresses the immune system (immunosuppressants), especially if found and treated early.

# Types of supportive care

## 4. Management of treatment side effects

### Radiotherapy

A special form of radiotherapy called stereotactic radiotherapy is sometimes used to treat kidney cancer. Stereotactic radiotherapy uses a high dose of radiation targeted at the tumour. This aims to kill all the cancer cells in that area.

Radiation can cause side effects during or immediately after treatment. They tend to disappear gradually after radiation is complete. Possible immediate side effects depend on the area being treated. They include:

- Extreme tiredness (fatigue).
- Reddening, irritation and swelling of the tissues in the treatment area.
- Loss of body hair in the treatment area.
- Feeling or being sick (nausea and vomiting).
- Diarrhoea.
- Headaches.

Stereotactic radiotherapy is very precise and targets the tumour with limited damage to healthy surrounding tissue. This minimises the possible side effects of the treatment.

Tell your healthcare team about any side effects to treatment as soon as possible. The earlier they are reported, the easier they are to treat and manage. For some side effects, you might need to see a specialist doctor or nurse to help you manage them, such as an endocrinologist, palliative care doctor or nurse, a dietitian, or a physiotherapist.

If you have other conditions, such as heart disease or lung disease, you might need to see a doctor specialising in these conditions to support you during your cancer journey. Some cancer treatments might make other health conditions worse, like high blood pressure, so it is important that you see a specialist doctor to help you manage these side effects.





## 5. Co-ordinated care for patients with existing illnesses or disabilities

Some patients with cancer also have other illnesses or disabilities (called co-morbidities). As the population of patients with cancer continues to age and cancer becomes more of a long-term (chronic) condition, more patients have co-morbidities during their kidney cancer journey. Co-morbidities can include conditions such as high blood pressure, heart disease, diabetes, other types of cancer or arthritis etc. These conditions result in complications when treating kidney cancer.

If you have another illness or disability, your treatment will need to be coordinated by your healthcare team to manage your conditions effectively. Usually, the cancer nurse specialist manages patient needs, especially when they have other illnesses or conditions.

Your care and treatment will be managed by a multidisciplinary team (MDT) of healthcare professionals, specialising in the treatment of your cancer and other illnesses or disabilities. For example, a cardiologist if you have heart disease, or a rheumatologist for arthritis. This team may also include your family doctor. Successful management of your cancer together with any other illnesses or disabilities needs good communication between all the healthcare professionals involved in your care. Test results and side effects to cancer treatment need to be shared between the different specialities.

If your comorbidities are not managed effectively, this could affect the outcomes of cancer treatment. Cancer nurse specialists should assess comorbidities through talking with your family doctor and other healthcare professionals. Your cancer healthcare team needs to communicate and work closely with your family doctor.

It is important for cancer nurse specialists to have a care plan in place for managing other illnesses or disabilities. These care plans should be personalised to you and your healthcare needs. Personalised care plans must consider both cancer and non-cancer illnesses. You need to be told how to manage non-cancer illnesses during cancer treatment.

Talk to your healthcare team or cancer nurse specialist if you are concerned about the treatment of any non-cancer illnesses or disabilities during your kidney cancer treatment and journey. You especially need to talk to your cancer nurse specialist about any side effects to cancer treatment that could make your other illnesses worse or any medicines that you take regularly that could interact with your cancer treatment to cause side effects or reduce its effectiveness.



# Types of supportive care

## 6. Management of psychological and emotional support

When you have kidney cancer, life can be overwhelming, challenging and often lonely. Worry, depression, fear of your cancer coming back or simply 'not feeling right' are common to people living with a kidney cancer diagnosis. Many people suffer in silence, rarely talking about how they are feeling with either their healthcare team or family members and carers. However, people who discuss how they are feeling often find their worries are helped simply by talking about it.

Conversations can identify simple lifestyle changes that can make a positive impact on your emotional wellbeing. And talking about how you are feeling with a healthcare professional can lead to clinical support that may transform your kidney cancer journey. As well as improving mental health, a sense of wellbeing and a positive attitude can also improve treatment outcomes.

Some patients will be able to draw on their own inner resources to help them cope, while others gain emotional support from family members and other patients in patient support groups. Some patients may benefit from therapies, such as person-centred counselling, meditation, relaxation, and cognitive behavioural therapy (CBT).

If you are feeling overwhelmed and would like some help, talk to your healthcare team, family members, and carers or your local patient support organisation about the psychological support that is available to you in your country.



## 7. Diet and nutrition

At all stages during your kidney cancer journey, a healthy, well-balanced diet will help to improve your wellbeing and your quality of life. A healthy diet will keep your strength up, prevent extreme tiredness, help fight infection, help the repair and growth of normal body tissues, and stop body tissues from breaking down.

A good diet is key to our wellbeing, regardless of whether we are healthy or ill. A proper diet helps us feel better and cope with some of the symptoms and side effects caused by the cancer or treatments.

When you have cancer, you need a healthy balanced diet. It is essential to eat a good, varied diet and have a healthy lifestyle at all stages of the disease, from the moment of diagnosis. A healthy diet will help you cope better with treatments and any physical complications that occur, speed up recovery and improve your quality of life. A healthy diet will also help your kidneys to function properly. Your kidneys remove waste and extra water from your blood, they control blood pressure, keep bones healthy and control the acidity of your blood. What we eat influences how our kidneys work. Kidney cancer stops the kidneys from working properly, so you may need to change your



diet. You might need to see a dietitian for support and advice on a healthy diet for people with kidney cancer.

Side effects to treatment and the symptoms of the cancer may cause changes to the way our food is digested, causing diarrhoea, constipation, nausea, or changes to our sense of taste, etc. Some changes to your diet can be of great help, such as eating more fibre, avoiding spicy or acidic food, seasoning food differently, or changing the size or the frequency of your meals. Cancer can make you feel scared, worried, and uncertain. This can affect your eating habits and your appetite. You may need the help and support of a dietitian to be able to cope and to help you get the best diet.

Eating is a social activity and food is an essential part of many cultures. When we sit around a table we come together to talk, socialise, share our lives, and celebrate. It is important to continue enjoying these moments, which is why you might want to have support for eating problems so you can continue to make the most of life.

# Types of supportive care

## 8. Palliative care

The term ‘palliative care’ was initially used for people with cancer, but now includes people with other life-limiting or life-threatening conditions.

Palliative care is defined by the World Health Organisation as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological, and spiritual”.

Palliative care aims to improve quality of life by looking after the whole person, their physical, mental (psychological) and spiritual wellbeing, as well as taking care of their family members and carers.



Palliative care:

- Provides relief from pain and other distressing symptoms.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help people to live as actively as possible and to help the family cope during the cancer pathway from diagnosis, through treatment and beyond.
- Uses a team approach to meet the needs of patients and their families, including bereavement counselling.
- Enhances quality of life and the course of the illness.

Palliative care should not only be used at the end of life. Kidney cancer patients may need access to palliative care services from diagnosis, for help in dealing with social, spiritual, and psychological issues. Carers and family members may also be offered emotional and spiritual support to ensure a whole person (holistic) approach to palliative care.

In some countries, palliative care is more accurately described as supportive care since palliative care is thought of by many people as care that is given at the end of life. The terms palliative care and supportive care are sometimes both used to describe the same thing.

## 9. Social care and support

The social impact of cancer is considerable and reaches beyond the patient, immediate family and carers to friends, associates, and work colleagues. You might need support from health and social care services to help maintain your social networks, provide support with personal care, cleaning, and shopping, provide care for vulnerable family members, provide advice on employment issues, and help you get financial benefits.

Communication between your healthcare team and social care services and the voluntary sector is essential to make sure that your needs and the needs of your family and carers are met.

Talk to your healthcare team about how to access social care and financial support for you, your family, and carers during your cancer journey. Your local kidney cancer patient support organisation might also be able to help you with social support, and advice about financial support for your care and treatment (see also section 15. Financial and employment advice/support).



# Types of supportive care

## 10. End of life care

End of life care is a term used to describe the care provided in the last year of life. Health or social care professionals can usually tell when a person is approaching the end of their life because their health gets worse, their cancer progresses, they are not able to look after themselves, they lose weight, they have cancer symptoms when on treatment, they are often too frail for active cancer treatment to continue, or the person agrees to stop treatment and focus on quality of life.

End of life care includes all the supportive care services that focus on whole person care and quality of life, such as management of the symptoms of the cancer, management of side effects to cancer treatment, psychosocial support, spiritual support, and complementary therapies to improve the wellbeing of the patient and their family members and carers.

People with a terminal illness who are approaching the end of their lives will be emotionally distressed, worried, and fearful. This is also the case for the family members and carers. Your feelings might be so acute, that you are unable to express how you are feeling or what you are thinking. You might feel that you have no control over your own life. At this time, end of life care for you and your family

members and carers is very important, and you might need access to several end-of-life professionals during this time.

End of life care should help you to live as well as possible until you die and to die with dignity. You should be allowed to express your wishes and preferences, and these should always be considered by your healthcare team. Your care should be planned based on your needs and preferences. Your healthcare team should also support your family members, carers or other people who are important to you.

You have the right to express your wishes about where you would like to receive care and where you want to die. You can receive end of life care at home, in a care home, hospice or hospital, depending on your needs and preference.

You need to have discussions with members of your health or social care team, so that you can communicate your needs, wishes and preferences at the end of your life. Your healthcare team should be sensitive to your situation and state of mind. It will help your healthcare team understand your priorities and wishes. They should support you to make informed decisions about your care and treatment. Your needs and preferences can change quickly towards the



end of life, so effective communication is essential to make sure your healthcare team understand your needs, and these needs can be met. Good end-of-life discussions with your healthcare team can help you live well during the last months or days of your life.

When you approach the end of your life, you might have discussions with your health or social care team, close family members, or carers about a 'do not resuscitate' (DNR) order. A DNR decision focuses specifically on whether attempts will be made by your healthcare team to revive you if you stop breathing or your heart stops. If it is agreed not to resuscitate, the healthcare team will not attempt to revive you. A DNR order should not affect other treatment decisions. In other words, just because it has been decided that the healthcare team will not attempt to restart your heart and/or breathing (called cardiopulmonary resuscitation, CPR), it does not mean other methods of treatment should not be attempted either.

Your health and social care team will also be able to give you and your family advice about writing your will and planning your funeral.

Writing your will is one of the most important parts of planning for the end of life. By making a will you can express your final wishes and decide what you would like to leave your family and friends. Several people can help you write your will, including solicitors, professional will writers, charities, and banks. You can even write your own will. For your will to be legal, you need to be of sound mind, and it must be written voluntarily. Additionally, you must sign it in front of two independent witnesses who must also sign the will.

Planning your own funeral can give you peace of mind. It will help your family and friends remember you after you die. Most people avoid talking about their funeral until it is too late or leave it until they are approaching the end of their lives. Making plans for your funeral will help family and friends at a time of great distress and upset. It will help them make important decisions about celebrating your life in meaningful ways that are important to you. A funeral director can help you think about your options and give you advice. Some charities and hospices can also help you and your family with funeral planning.

# Types of supportive care

## 11. Support for family members and carers

Sometimes, family members and carers find a diagnosis of kidney cancer even harder than the patient. They may live with guilt of not being able to prevent their loved one from getting cancer.

The experience of a cancer diagnosis can be draining for close family members. Like the patient, family members can feel bewildered and 'numb' while they are processing the diagnosis.

Family members and carers may also need support when they are really struggling with the realities of living with a loved one with kidney cancer. They might struggle with daily living and what they may face in the future. Routines and treats, like lunches out and short holidays, can help keep things as normal as possible, not allowing the cancer to change everything about family life.

Some patients aren't keen to receive support outside the family, for various reasons, such as pride, culture, and vulnerability. This puts a lot of burden on the family. Some family members are happy to support their loved one and it brings them closer; however, for others the opposite can be the case and the disease becomes a burden.

Psychosocial support for family members and carers is very important to help them come to terms with the diagnosis of cancer. Family members and carers can gain support through online kidney cancer forums and Facebook groups.

Communication between family members and carers, and the healthcare team can help them understand their role in caring for the patient. Good communication can also make the family members and carers more confident about giving care, especially if they receive practical information from healthcare professionals. Family members and carers who receive support can be better prepared to care for their loved one at home or in the community.



## 12. Rehabilitation (physiotherapy and exercise)

Cancer and its treatment, especially surgery, can cause physical problems, problems with your mobility, and affect your quality of life. These problems can make it harder to do daily activities, return to work, or continue cancer treatment. They can have a lasting effect on your health and your quality of life, and the quality of life of your family and carers. Cancer rehabilitation can help with these problems.

Cancer rehabilitation helps you stay as active as possible and take part in family, work, and other life roles. Cancer rehabilitation can also reduce the symptoms of cancer, help you recover from surgery and reduce treatment side effects. Rehabilitation can help you stay as independent as possible and help you live your best life.

In some countries, cancer rehabilitation is given by rehabilitation healthcare professionals, such as a physiotherapist or exercise physiologist, that you can work with during treatment, follow up care, or long-term survival. In some countries, cancer rehabilitation is given by cancer doctors and nurses.

Talk with your healthcare team about cancer rehabilitation before you have surgery and at any time you notice a

change that makes you less active or makes everyday tasks more difficult, like walking, pain, weakness, or trouble thinking clearly. It is important to address any changes you notice as early as possible, so they do not get worse.

You might also like to ask your healthcare team about cancer rehabilitation before surgery and cancer treatment begins to help you prepare physically and mentally for treatment. You can then be monitored after surgery, throughout treatment and beyond to catch issues before they become serious. This approach can improve your quality of life and it can reduce symptoms and problems that can impact your life.

Cancer and cancer treatment can cause many kinds of physical problems. Cancer rehabilitation can help with many of them, such as pain, swelling, and weakness, mobility, balance and flexibility, skin changes, numbness and tingling in hands or feet, extreme tiredness, sexual health problems and problems with chewing and swallowing. Cancer rehabilitation can also help with mental problems, such as multitasking, thinking clearly and memory trouble. Talk to your healthcare team if you notice any of these physical or mental problems so you can get the help and support you need from a specialist healthcare professional.

# Types of supportive care

## 13. Complementary and alternative therapies

**Complementary therapies** are used in addition to standard medical treatments to improve quality of life and wellbeing. Complementary therapies may help you feel better, feel less stressed, tense, and worried, sleep better, cope better with cancer symptoms and side effects of treatment, and feel more in control of your life.

Complementary therapies that might be able to help you during your care and treatment include mind-body therapies such as yoga, meditation and hypnotherapy, massage and reflexology, acupuncture, therapies using herbs and plants (please talk to your healthcare team to make sure there are no interactions with your anti-cancer medication), and therapies using supplements or diet.

However, if there is any chance that the kidney cancer has spread to your bones, chiropractic treatment or osteopathy would not be a good idea.

Many people also find talking, counselling and patient support groups a good source of support.

There are many reasons why people use complementary therapies. Some people find they help them cope with the stress of cancer and its treatments. Many therapies are relaxing and may improve your mood when you are not feeling your best.

Some people build a strong relationship with their complementary therapist, which can be another benefit. Having someone who listens to you may help you cope with difficult feelings.

Getting this support can help you feel more in control. Some people see using complementary therapies as a positive way of looking after themselves.

Some complementary therapies are done as part of a group. This can be a good way to meet other people with similar experiences, in a positive setting.

If you decide that complementary therapies would help you cope with your kidney cancer and treatment, ask your healthcare team which complementary therapies are available to you through your supportive care team at your hospital or in the community. Alternatively, you can get in

touch with your local patient support organisation who might be able to give you advice on how to access complementary therapies in your country.

**Alternative therapies** are therapies that are not supported by scientific or medical evidence and have not been licensed to treat cancer. They are not standard medical treatments and lack clinical evidence to show they are effective against cancer. Alternative therapies are usually taken instead of the treatments prescribed by your doctor.

Friends and relatives may suggest alternative therapies, or you might find stories about them on the Internet or social media. Alternative therapies are usually sold to cancer patients for profit. Alternative therapies can be harmful, especially if used with prescription medicines.

Some examples of alternative therapies include homeopathy, coffee enemas, high-dose vitamins, ground apricot kernels, herbal medicines, supplements, or extreme diets. It is important that you let your healthcare team know if you are considering alternative therapies for cancer in case you become ill.



# Types of supportive care

## 14. Spiritual support

A diagnosis of cancer can raise unsettling questions for some patients. They will seek to re-examine their beliefs, whether philosophical, religious, or spiritual in nature. Patients and their families or carers should have access to healthcare professionals who are sensitive to their spiritual needs.

Living with cancer can feel like living with uncertainty. Sometimes that uncertainty can lead you to think about questions in the context of your personal spirituality. You may have been a spiritual or religious person before you had cancer, or it may be something you did not think about before. You do not have to be religious to get spiritual support; spiritual support can help no matter what your beliefs are.



Spiritual support can help you identify sources of strength and strategies for coping. Finding ways to cope with and process your experience is an important part of your overall cancer care. Many patients, and their loved ones, report that spiritual support and care helped them during cancer. Spiritual support can help you cope with the symptoms of your cancer and the side effects of treatment. Spiritual support can also help you cope with your emotions, feeling overwhelmed, family problems, loneliness, or being angry with God or the universe for your cancer.

A chaplain or spiritual advisor usually provides spiritual care and support. This person might be a member of your healthcare team, or you can find spiritual support in your religious community, if you have one. You can also ask what support is available from the community.

Chaplains or spiritual advisors can help you identify sources of strength for coping. They also identify and advocate for what matters most to you in your cancer journey. Chaplains and spiritual advisors are also trained to talk about life, death, legacy planning, and finding purpose. You can also receive spiritual support from family, carers, and friends.

Your chaplain or spiritual advisor can work with other members of your healthcare team. They might be able to put you in touch with a counsellor or other mental health professional, or social worker.

Your family members and carers can also get spiritual support to help them cope with a loved one with cancer. Family members and carers might be afraid of losing you, fear that they have somehow caused the cancer, feel extremely tired, be frustrated, or feel angry about the situation. Talking with a chaplain or spiritual advisor can help family members and carers understand what they are feeling. It can also help them find support and answers.



# Types of supportive care

## 15. Financial and employment advice/support

A diagnosis of kidney cancer can change your financial situation. It may mean you need to stop working or work less. You might need to spend more money on transport to hospital, hospital parking or overnight accommodation for you and your family or carer for hospital appointments. Depending on your situation and the government in your country, you may be able to get benefits or other financial support.

Benefits are payments from the government to people who need financial help. When you are affected by kidney cancer, you may be able to get benefits to:

- Help with the extra costs because of your care and treatment.
- Support you if you need to stop working.



The benefits system in some countries can be hard to understand. Your local kidney cancer patient support organisation, and some national cancer charities will have information to help you get the financial support you need throughout your kidney cancer journey. Some charities also offer financial support to cancer patients in need, depending on their financial situation. You can also speak to your healthcare team or social worker for advice about financial support and where to get it.

You may need to take time off work to have tests, appointments, and treatments. You may also need time to cope with your feelings, for example, if you feel worried, emotionally distressed, upset, or fearful. Everyone deals with their feelings and a diagnosis of cancer differently: Some people stop working to focus on treatment and time with family and friends. Some stop working during treatment until they feel ready to go back to work. Others carry on working, perhaps with reduced hours or changes to their job.



If you are employed by an organisation and need to take time off sick, you may be able to get sick pay. Sick pay varies according to the employer. Also, some countries have government schemes that offer sick pay to people with cancer who are not able to work. Your employer should try to support you at work by making reasonable adjustments to help you do your job during and after cancer treatment, such as a phased return to work, flexible working hours, working from home (if appropriate), time off for hospital appointments, light duties, and extra breaks to help you cope with tiredness.

If you are self-employed, and you need to reduce your working hours, your business could be affected. You may not have the same kind of support that someone working for an organisation might have. But you may be able to work in a more flexible way and set your own pace.

Some governments offer advice and practical support if you have a long-term health condition that is affecting your job. There are also local charities and organisations that can help you with your employment needs. Please contact your local patient support organisation or speak to your social worker or specialist cancer nurse for advice about returning to work during or after kidney cancer treatment.



# My healthcare team

Specialist supportive care teams provide care in hospital. These multi-disciplinary teams may be made up of doctors, nurses, physiotherapists, psychologists, dietitians, social workers and chaplains, or the service can be provided by a specialist cancer nurse. They provide support directly to patients, family members, and carers. In some countries, occupational therapists help manage cancer symptoms and treatment side effects so that people can cope with the activities of daily living to improve their wellbeing.



## Good communication with your healthcare team

It is important that you and your family and carers have good communication with the members of the healthcare team that will be caring for you and treating you. Your cancer nurse or doctor should explain the role of each member of your hospital healthcare team (see page 45).

Due to language barriers or for cultural reasons, a translator may be needed. Language barriers, cultural and information needs should be discussed during your first meeting with your healthcare team. Your cultural and social background are important when talking about cancer care and treatment.

It is important that cancer nurses or doctors use plain language to when talking about cancer care and treatment with you and your family and carers. They should use every day talk and not use health jargon. They should define all medical words or terms. They should talk to you directly (e.g., say 'you' instead of 'the patient' or 'a person'). If you or your family or carers do not understand what is being said, do not be afraid to ask the cancer nurse or doctor to explain again.

You and your family and carers will face many issues when you are diagnosed with kidney cancer. You might be worried about treatments because they have severe side effects that can affect your quality of life, they can be difficult to administer, e.g. infusions, and they are expensive.

Decisions about treatments can be very hard to make. You and your family or carers might want to be involved in making decisions about your care and treatment. Or you may want to leave the treatment decisions to your healthcare team. Good communication can help you and your family or carers make these decisions together with your healthcare team, and improve your wellbeing and quality of life.

Being diagnosed with kidney cancer can be overwhelming. Learning about the disease and treatment options can help you and your family or carers make the best decisions about your care and the various treatments that are available for you.

You are the most important and powerful person involved in your own healthcare. Only you and your family, or carers understands the effect of these treatment decisions on your life.

You can decide who is involved in your care and treatment. Family members and carers can help you make better decisions about your care and treatment. This will help them support you to make the best decisions to live a long and good quality life. You should have a say in how much help you want from family members and carers when making decisions.

Family members or carers can be a great support during hospital appointments. They can be there to ask questions about care and treatments, and where to get support. They can also support you by writing down key information about the cancer or the results of tests. They may be able to record the appointment so that you can listen to what was said in your own time.

# My healthcare team

Studies show that when patients and healthcare professionals communicate well during the care and treatment of kidney cancer patients, supportive care is better, and your wellbeing and quality of life are improved.

You need to have good communication with your cancer doctor and nurse. The more questions you ask, the more you will understand. This will make you feel in control and confident about the decisions you make.

Talking with your cancer doctor or nurse will also help them understand what is important to you. Tell them about your worries and what matters to you most.

You may have one main doctor, or many healthcare professionals involved with your care and treatment.

However, the most important person in your healthcare team is you! With the help of this decision aid, you can work with your healthcare team to learn about kidney cancer, treatment options and supportive care. Together you can make decisions that may improve your health and wellbeing.

## Who are the members of my healthcare team?

Treating kidney cancer can require the skills of many different healthcare professionals. Your healthcare team might include some of the healthcare professionals listed in the table opposite.

In some countries, healthcare professionals work together in a multidisciplinary team (MDT). The MDT meets regularly to discuss your treatment and care. In other countries, they might work separately:



## Healthcare team

### General practitioner (GP)

A family doctor who is based in the community and treats patients with minor or chronic illnesses. Can help manage your cancer symptoms, treat side effects, and assist with coordinating your care in the community.

### Urologist

A surgeon who specialises in treating diseases of the kidney, bladder, and prostate (the urinary system). A uro-oncologist specialises in treating cancers of the urinary system, including kidney cancer. The urologist is responsible for taking biopsy samples.

### Medical oncologist

A doctor who diagnoses and treats cancer.

### Radiologist

A doctor who specialises in diagnosing disease by using x-ray scans, ultrasound, CT scans and MRI scans.

### Radiation oncologist

A doctor who specialises in treating cancer with radiotherapy (including stereotactic radiotherapy).

### Cancer nurse specialist or cancer nurse

A specialist nurse who supports you through diagnosis and treatment. The nurse will manage your care, give you medication, and provide information about your kidney cancer. Helps relieve symptoms, manage pain, and improve your quality of life.

### Pathologist

A specialist doctor who studies cells under a microscope and who diagnoses the stage, grade, and type of kidney cancer you have.

### Pharmacist

Prepares and gives out medicines to patients.

# My healthcare team

<b>Supportive care team</b>	
<b>Cancer nurse specialist or cancer nurse</b>	A specialist nurse who supports you through diagnosis and treatment. The nurse will manage your care, give you medication, and provide information about your kidney cancer. Helps relieve symptoms, manage pain, and improve your quality of life.
<b>Palliative care doctor or nurse</b>	Helps relieve symptoms, manage pain, and improve your quality of life.
<b>Dietitian</b>	Gives advice for a healthy, well-balanced diet to maintain strength and reduce fatigue.
<b>Physiotherapist</b>	Helps with rehabilitation after surgery and management of side effects to cancer treatment.
<b>Psychologist</b>	Helps people cope with stress and long-term illness.
<b>Exercise physiologist</b>	Helps improve performance and fitness level through exercise.
<b>Social worker</b>	Provides social support to the patient, family, and carers.
<b>Healthcare chaplain or spiritual advisor</b>	Provides spiritual care
<b>Occupational therapist</b>	Helps people deal with the activities of daily living to improve their wellbeing.
<b>Hospice or care coordinator</b>	Provides a link between patients and the range of end-of-life support services available in the local community. Supports patients at the end of life, their families, and carers to find health and social care services.

# Charities and organisations for patients, families, and carers

In many countries, there are active online patient support organisations for kidney cancer patients, their families, and carers. See the [IKCC website](#) for a kidney cancer patient support organisation in your country.

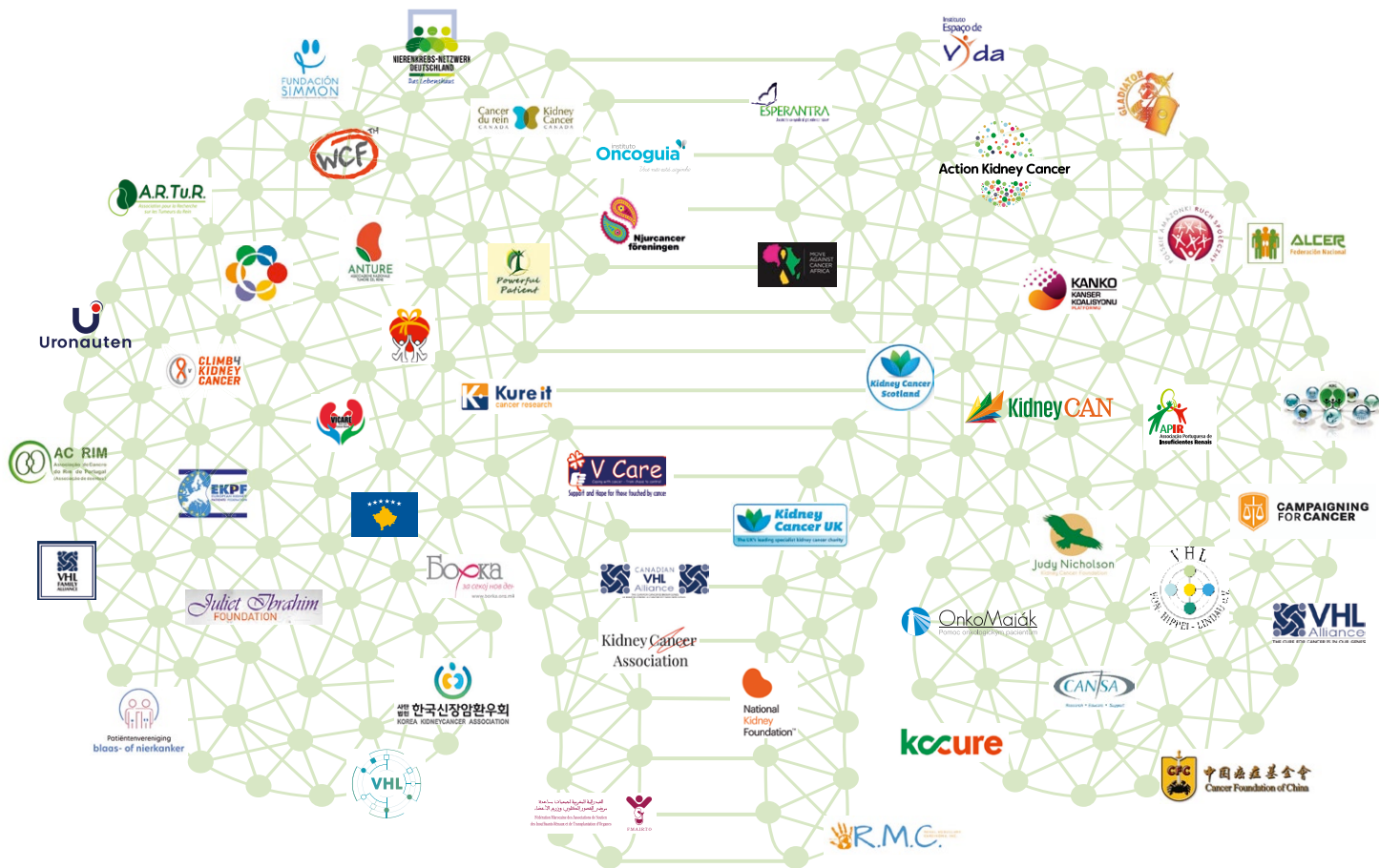
The number of online kidney cancer patient support organisations is increasing. Many have online chat forums to allow people to share their experiences and talk about their feelings and get support from other kidney cancer patients, carers, or survivors. Some forums are led by healthcare professionals or are overseen by experienced patients who make sure the information shared is accurate and to stop scammers and commercial advertising.

Some kidney cancer charities or patient support organisations run local face-to-face meetings of small groups of patients who come together to share their experiences and support one another. Sometimes, these groups are organised by hospitals and are led by a specialist cancer nurse. Support groups can have a positive effect on those who attend. Such as improvement in mood, acceptance of the disease, and better pain control. Support groups can help people to share their feelings, make friends, learn how to cope, and live with the diagnosis of kidney cancer, as well as receive good quality, up-to-date, evidence-based information about the disease.

Most kidney cancer charities or patient support organisations have telephone helplines or a dedicated email address for personal one-to-one support of patients and their families and carers. Patients or family members and carers can use these helplines to get answers to specific questions or advice on treatments, side effects or living with kidney cancer from an experienced patient advocate, another patient or survivor, or a specialist cancer nurse without sharing their personal information on an online forum.



# Charities and organisations for patients, families, and carers





My questions



# My questions

The information you have learned about supportive care has probably raised some questions. It can help to write them down at the appropriate pages in this book. By talking them through with your doctor and nurse, your questions can help you decide which types of supportive care are right for you.

Talking with your healthcare team will also help them understand what is important to you. Tell them about your worries and what matters to you most.

The lists of questions on the following pages may help you understand the types of supportive care available to you throughout your kidney cancer journey. Before your hospital appointment, think about the questions you may want to ask. During your appointment, write the answers in the space provided in the table on the following pages. Talk about supportive care with your family members and carers and add any other questions you would like to ask which are not listed. Making notes during your appointment can be helpful, especially if you are reviewing information after your visit.

Taking someone with you to appointments can be very useful, as they can take notes while you concentrate on what the doctor is saying. You may also ask your doctor for permission to record the conversation so you can listen again later.

Contact your local kidney cancer patient support organisation for good up-to-date information and support. See the [IKCC website](http://www.ikcc.org) (www.ikcc.org) for a list of kidney cancer patient support organisations.



# Questions you might like to ask your doctor

Questions to ask your healthcare team	Please fill in your answers	<input checked="" type="checkbox"/>
<b>Can you give me high quality, written information about the diagnosis, care, and treatment of kidney cancer in plain language for me and my family and carers to read in our own time?</b>		
<b>Can you recommend some high-quality websites/charities/patient support organisations where I can get support and information for my cancer?</b>		
<b>What are the common symptoms of kidney cancer?</b>		
<b>How can these symptoms be prevented or treated?</b>		

# Questions you might like to ask your doctor

<b>Questions to ask your healthcare team</b>	Please fill in your answers	<input checked="" type="checkbox"/>
<b>What are the common side effects to the treatment I am having?</b>		
<b>How can these side effects be prevented, relieved, or treated?</b>		
<b>Who should I contact if I feel worse or notice a new side effect?</b>		
<b>How can I get in touch with you if I need to?</b>		
<b>Will cancer treatment affect my ability to live on my own?</b>		

Questions to ask your healthcare team	Please fill in your answers	<input checked="" type="checkbox"/>
Will cancer treatment affect my memory or the way I think?		
Will cancer treatment affect how well I am able to live my life?		
Will I need to give up work because of the cancer or its treatment?		
What supportive care services are available to me at this hospital?		
Does this hospital have specialist healthcare professionals for supportive care?		

# Questions you might like to ask your doctor

<b>Questions to ask your healthcare team</b>	Please fill in your answers	<input checked="" type="checkbox"/>
<b>Where else can I get supportive care?</b>		
<b>Can I have supportive care at home or close to home?</b>		
<b>Who can I speak to about any financial worries that I have about my care and treatment?</b>		
<b>Where can I get financial help with travel costs, time off work, accommodation, childcare etc. for me and my family and carers for attending hospital appointments?</b>		
<b>Will my health insurance cover the costs of supportive care?</b>		

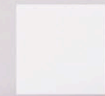
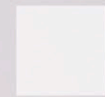
Questions to ask your healthcare team	Please fill in your answers	<input checked="" type="checkbox"/>
Who can I talk to if I am feeling scared, stressed, or depressed, or I am having problems coping?		
What types of emotional or spiritual support are available for me in the hospital?		
Where else can I get emotional or spiritual support?		
Can my social worker or cancer nurse give spiritual support?		
Are my family members and carers able to get supportive care at this hospital?		

# Questions you might like to ask your doctor

Questions to ask your healthcare team	Please fill in your answers	<input checked="" type="checkbox"/>
Where else can my family members and carers get supportive care?		
Other questions	Please fill in your answers	<input checked="" type="checkbox"/>



# My decision



## Summary

Below is a summary of the possible benefits and disadvantages of supportive care:

Possible advantages of supportive care	
<b>1. Control the symptoms and complications of kidney cancer</b>	Your specialist cancer nurse or palliative care team will be able to help control the symptoms of kidney cancer to improve your quality of life, and the life of your family, and carers.
<b>2. Prevent or reduce side effects to treatment</b>	Your specialist cancer nurse or palliative care team will be able to treat and manage the common side effects to kidney cancer treatments such as cancer medicines, radiotherapy, surgery etc. so they affect your quality of life as little as possible. Effective management of side effects improves tolerance to treatments and increases the benefits of treatment.
<b>3. Easing the burden of kidney cancer</b>	Spiritual support can help you cope with the symptoms of your cancer and the side effects of treatment. Spiritual support can also help you cope with your emotions, feeling overwhelmed, family problems, loneliness, or being angry with God or the universe about your cancer.
<b>4. Psychosocial support during the cancer journey</b>	Talking about how you are feeling with a healthcare professional or trained counsellor can transform your kidney cancer journey. As well as improving mental health, a sense of wellbeing and a positive attitude can also improve treatment outcomes.
<b>5. Support with a healthy lifestyle, diet, and exercise</b>	A healthy balanced diet will help you cope better with treatments and any physical complications that occur, speed up recovery, give you more energy and improve your quality of life.
<b>6. Cancer rehabilitation</b>	Helps you stay as active as possible and take part in family, work, and other life roles. Can reduce the symptoms of cancer, help you recover from surgery and reduce treatment side effects.

## Possible disadvantages of supportive care

<b>1. Not all supportive care services are available in your hospital</b>	You might need to be referred to a different hospital or clinic to receive the supportive care services that you need and that are not available in your hospital.
<b>2. Financial costs of supportive care</b>	Some supportive care services might need to be paid for in addition to your routine hospital care. If you have a national health service, some supportive care services might not be paid for by the state and only available privately.
<b>3. Finding supportive care services in the community</b>	If not available in your hospital, you might need to search in the community for the type of supportive care that you prefer or need.
<b>4. Communication with your supportive care team</b>	Good supportive care requires effective communication between you, your family members and carers and your healthcare team.
<b>5. Late reporting of cancer symptoms and side effects</b>	Late reporting of cancer symptoms and side effects to your healthcare team will make them more difficult to treat successfully and manage.
<b>6. Quality and availability of supportive care</b>	The quality and availability of supportive care might vary between hospitals and between countries. Not all hospitals will have the same level of supportive care available to cancer patients.



# My resources



## Getting additional support

Cancer and its treatment can have a huge physical and emotional effect on you. It is important to look after yourself. This includes eating a well-balanced and healthy diet, not smoking, doing regular exercise, and seeking help if you feel depressed or worried. There are healthcare professionals who can help guide and support you with these aspects of your life.

Family or friends are another valuable source of support, whether it's helping with the shopping, coming to doctor appointments with you or simply being with you. Let your family and friends support you. Your cancer diagnosis will also affect your family. It is likely that your closest family member or main carer may also need help and support.

Your family or friends can also help you with deciding what support you need. Discussing your needs, preferences and wishes with family members or friends can help with this decision. Friends or family may be able to come with you to hospital appointments and can help by taking notes while you concentrate on what the doctor is telling you.





Many people find that it's helpful sharing their experiences and knowledge with other people who have cancer or talking to someone trained in supporting people with kidney cancer. You may consider contacting a kidney cancer patient support organisation to get information about kidney cancer and how to navigate your way around the healthcare system in your country.

Being a carer for a loved one with cancer can be rewarding, but it can also be tiring, stressful, and cause you a lot of worry. It is important that you look after yourself and take some time just for you. And it's important that you get some help and support too.

By the time you come to this section you should have a good understanding of supportive care and its benefits and disadvantages. More information about the treatment of kidney cancer can be found in our *My Treatment, My Choice* decision aids, which can be found on the [IKCC website](#).

You might find it helpful to keep a personal file of important reports and documents about your kidney cancer care and treatments, including the following:

- Important medical reports and documents.
- A list of all the drugs you may be prescribed.
- Contact information for your healthcare team.
- Notes on clinical appointments and consultations.
- Questions you want to ask your healthcare team.
- A record of symptoms and side effects.

# My resources

## Further reading

[IKCC – My Treatment, My Choice decision aids](#)

[Multinational Association of Supportive Care in Cancer](#)

[World Health Organisation – Palliative care](#)

National Health Service (NHS) England – [What end of life care involves](#)

NHS Inform – [Palliative care](#)

Cancer.net – [Coping with cancer](#)







Glossary

**Acupuncture:** A form of complementary therapy in which fine needles are placed in the skin at specific points along what are lines of energy (meridians), used in the treatment of various physical and mental conditions.

**Adrenal insufficiency:** A disorder that occurs when the adrenal glands don't make enough of certain hormones. These include cortisol, sometimes called the 'stress hormone', which is essential for life.

**Alternative therapies:** Treatments that are not standard medical treatments, and which might not have been shown to be effective against cancer. Alternative therapies are taken instead of the treatments recommended by your doctor.

**Anxiety:** A feeling of worry, nervousness, or unease about something with an uncertain outcome.

**Cancer nurse specialist:** A specialist nurse who supports you through diagnosis and treatment. The nurse will manage your care, give you medication, and provide information about your kidney cancer. Helps relieve symptoms, manage pain, and improve your quality of life.

**Cardiopulmonary resuscitation (CPR):** A medical procedure involving repeated cycles of compression of the chest and artificial breathing, performed to maintain blood circulation and oxygenation in a person whose heart and/or breathing has stopped.

**Care plan:** A document detailing the person's needs, providing care to meet those needs, and supporting people in their preference for where they would like to be cared for and die.

**Chaplain or spiritual advisor:** Provides spiritual care.

**Chiropractic treatment:** The use of different techniques to treat problems with the muscles and joints, including spinal manipulation – using hands to apply force to the muscles, bones and joints of the spine and neck and gradually moving your joints into different positions.

**Cognitive behavioural therapy (CBT):** a type of psychotherapy in which negative patterns of thought about yourself and the world are challenged to alter unwanted behaviour patterns or treat mood disorders such as depression.

**Complementary therapies:** Therapies that complement standard medical treatments, improving quality of life and symptoms, e.g., mindfulness meditation, relaxation techniques, massage therapy, psychotherapy, prayer, yoga, and acupuncture.

**Colitis:** Swelling (inflammation) of the large intestine (colon) leading to diarrhoea.

**Co-morbidity:** When a person has more than one illness or disability at the same time.

**Constipation:** A condition in which there is difficulty in emptying the bowels, usually associated with hardened faeces.

**Counselling:** Professional assistance and guidance in resolving personal or psychological problems.

**Dietitian:** Gives advice for a healthy, well-balanced diet to maintain strength and reduce fatigue.

**Diarrhoea:** A condition in which waste matter from the digestion of food (faeces) is released from the bowels frequently and in a liquid form leading to dehydration if not treated early.

**Do not resuscitate (DNR) order:** A medical order written by a doctor to instruct healthcare professionals not to do cardiopulmonary resuscitation (CPR) if a patient stops breathing or their heart stops beating.

**End of life care:** A term used to describe the care provided in the last year of life.

**Exercise physiologist:** Helps improve performance and fitness level through exercise.

**Fatigue:** Feeling extremely tired and lack of energy.

**Haemorrhage:** Escape of blood from a damaged blood vessel resulting in excessive bleeding.

**Herbal medicines:** Medicines with active ingredients made from plant parts, such as leaves, roots, or flowers.

**Hernia:** Occurs when an internal part of the body pushes through a weakness in the muscle wall of the abdomen.

**Holistic:** Treatment of the whole person, considering mental and social factors, rather than just the symptoms of an illness.

**Homeopathy:** A form of alternative medicine in which illnesses are treated by very small amounts of natural substances that in larger amounts would produce symptoms of the illness. Homeopathy has not been proven to be effective against cancer.

**Hospice:** A home providing care for the sick or terminally ill.

**Hospice or care coordinator:** Provides a link between patients and the range of end-of-life support services available in the local community. Supports patients at the end of life, their families, and carers to find health and social care services.

**Hypnotherapy:** A type of psychological therapy that uses hypnosis to help treat certain mental and physical health conditions. Some therapists also use hypnosis to increase the effectiveness of other psychological treatments, or pain management.

**Hypophysitis:** Swelling (inflammation) of the pituitary gland, which may lead to diabetes, high blood pressure, irregular menstrual periods in women, low energy levels, and low sex drive.

**Hypothyroidism:** Underactive thyroid gland causing low metabolism.

**Immune-related side effects:** Autoimmune conditions that can affect any organ in the body after immunotherapy. They commonly involve the skin, endocrine glands (e.g., thyroid gland, pancreas), the gut, and liver, but can affect almost any organ system.

**Immunosuppressant:** A type of medicine that reduces the activity of the immune system.

**Kidney cancer:** Cancer that forms in tissues of the kidneys, including clear cell renal cell carcinoma (RCC), papillary RCC, chromophobe RCC and Wilms' tumour, a rare type of kidney cancer that usually develops in young children.

**Kidney disease:** A condition where the kidneys do not work as well as they should.

**Medical oncologist:** A doctor who diagnoses and treats cancer.

**Meditation:** To engage in mental exercise (such as concentration on breathing or repetition of a mantra) for the purpose of reaching a heightened level of spiritual awareness.

**Multidisciplinary team (MDT):** A group of healthcare and social care professionals who provide different services for patients in a co-ordinated way. Members of the team may vary and will depend on the patient's needs and the condition or disease being treated.

**Mindfulness:** A type of meditation in which you focus on being intensely aware of what you're sensing and feeling in the moment. Practicing mindfulness involves breathing methods, guided imagery, and other practices to relax the body and mind and help reduce stress.

**Nausea:** Feeling sick

**Neuropathic pain:** Nerve pain that can happen if your nervous system does not work properly or gets damaged.

**Non-steroidal anti-inflammatory drug (NSAID):** Medicines that are widely used to relieve pain, reduce inflammation, and bring down a high temperature.

**Occupational therapist:** Helps people deal with the activities of daily living to improve their wellbeing.

**Osteopathy:** A way of detecting, treating, and preventing health problems by moving, stretching, and massaging a person's muscles and joints. Osteopathy is based on the principle that the wellbeing of a person depends on their bones, muscles, ligaments, and connective tissue functioning smoothly together.

**Outcomes:** Outcomes are measures of health, e.g., response to treatment, occurrence, or recurrence of disease, a measure of wellbeing.

**Palliative care:** An approach that improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological, and spiritual.

**Palliative care doctor or nurse:** Helps relieve symptoms, manage pain, and improve your quality of life.

**Pathologist:** A specialist doctor who studies cells under a microscope and who diagnoses the stage, grade, and type of kidney cancer you have.

**Person-centred counselling:** A non-directive approach to talking therapy that requires the person to actively lead each therapy session, while the therapist acts mainly as a guide or a source of support for the person.

**Physiotherapist:** Helps with rehabilitation after surgery and management of side effects to cancer treatment.

**Physiotherapy:** The treatment of disease, injury, or deformity by physical methods such as massage, heat treatment, and exercise rather than by drugs or surgery.

**Psychologist:** Helps people cope with stress and long-term illness.

**Psychosocial:** How a person's thoughts and needs interact with social factors. How a person copes with their own thoughts and behaviours when interacting with friends, family, colleagues, and community.

**Psychotherapy:** The treatment of mental conditions by verbal communication and interaction.

**Pulmonary embolism:** A blood clot in the lung.

**Quality of life:** The standard of health, comfort, wellbeing and happiness experienced by a person.

**Radiologist:** A doctor who specialises in diagnosing disease by using x-ray scans, ultrasound, CT scans and MRI scans.

**Radiotherapy:** A cancer treatment that uses high doses of radiation to kill cancer cells and shrink tumours.

**Recurrence:** Cancer that has returned after a period during which the cancer could not be detected. The cancer may come back to the same place as the original (primary) tumour, or to another place in the body.

**Reflexology:** A type of massage used to soothe tension and treat illness, based on the theory that there are reflex points on the feet, hands, and head linked to every part of the body.

**Rehabilitation:** The action of restoring someone to health or normal life through training and therapy after illness or surgery.

**Relaxation:** The emotional state of low tension, in which there is an absence of arousal, particularly from negative sources such as anger, anxiety, or fear.

**Renal cell carcinoma (RCC):** The most common type of kidney cancer, a cancer that forms in the tissues of the kidney. Clear cell RCC is the most common subtype of kidney cancer.

**Resuscitate:** Revive a person from being unconscious after their heart and/or breathing has stopped.

**Self-help:** Everything that you and your family can do to help manage your cancer symptoms, treatments, lifestyle changes, mental health, and the social, cultural, and spiritual effects of your cancer. Self-help is ongoing and supported by your healthcare team, especially your cancer nurse.

**Sexual health:** Physical, emotional, mental, and social wellbeing in relation to sexuality, for example, the desire to have sex (sexual libido), the ability to have pleasurable sexual experiences, the physical ability to have sexual intercourse etc.

**Shared decision-making:** A process that ensures individuals are supported to make decisions that are right for them. It is a collaborative process through which a clinician supports a patient to reach a decision about their treatment. The conversation brings together the clinician's expertise, such as treatment options, evidence, risks and benefits, and the patient's preferences, personal circumstances, goals, values, and beliefs.

**Side effects:** Side effects are other effects on the body that may be related to the treatment. For example, a drug used to treat lung cancer may also cause a skin rash. Side effects can be caused by something else other than the treatment.

**Social worker:** Provides social support to the patient, family, and carers.

**Standard medical treatment:** Treatment that is accepted by medical experts as a proper treatment for a certain type of disease and that is widely used by healthcare professionals.

**Stereotactic radiotherapy:** A type of radiotherapy that uses a precise, high dose of radiation targeted at the tumour.

**Stomatitis:** Sore mouth

**Supportive care:** The prevention and management of the adverse effects of cancer and its treatment. This includes management of physical and psychological symptoms and adverse events across the continuum of the cancer experience from diagnosis through treatment to post-treatment care. Supportive care aims to improve the quality of rehabilitation, secondary cancer prevention, survivorship, and end-of-life care.

**Supportive care services:** The services provided by the supportive care team to support patients, family members, and carers in a hospital or hospice, e.g., psychosocial support, symptom control, side effect management, nutrition, rehabilitation, spiritual support, end-of-life care.

**Supportive care team:** A multi-disciplinary team of doctors, nurses, physiotherapists, psychologists, dietitians, social workers, and chaplains, who provide supportive care directly to patients, family members, and carers in a hospital or hospice.

**Symptom:** An indication that a person may have a condition or disease. Examples of symptoms include headache, fever, fatigue, nausea, vomiting, and pain.



**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).

**Urologist:** A surgeon who specialises in treating diseases of the kidney, bladder, and prostate (the urinary system). A uro-oncologist specialises in treating cancers of the urinary system, including kidney cancer. A urologist can be responsible for taking biopsy samples.

# Acknowledgements

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The IKCC is an independent international network of patient support organisations that focus exclusively, or include a specific focus on, kidney cancer. It is legally incorporated as a Foundation in the Netherlands. The organisation was born from a very strong desire among various national kidney cancer patient groups to network, cooperate and share materials, knowledge, and experiences.

As part of the *My treatment, My Choice* series of decision aids, this decision aid has been developed by the IKCC working in partnership with Action Kidney Cancer, a kidney cancer charity based in the UK.

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