My child has a kidney tumour

Information and support for parents
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About this booklet

Although many children with cancer can be cured it is still devastating to hear that your child has cancer. This booklet provides general information about kidney cancer (renal tumours) that occur in children.

It is designed to provide a reference to the information you have been given already, or will be given in the future, and will act as a reminder of discussions you have had with your child’s treatment team. Whilst this information may answer some of your questions, your child’s specialist doctor and/or nurse will give you more detailed information, and your child’s individual case should always be discussed with the team of healthcare professionals caring for your child.

This booklet contains information about the different types of childhood kidney cancer, the treatments that are used and their possible side effects. It also discusses how a cancer diagnosis can affect you, your child and the rest of the family. You may also find the CCLG booklet ‘Children and Young People with Cancer: A Parent’s Guide’ helpful.
Childhood kidney tumours

Childhood kidney cancers, also called renal tumours, are a group of different types of cancer that develop in the tissues of the kidneys.
There are two kidneys located on either side of the spine at the bottom of the rib cage. The kidneys’ major function is to filter and clean the blood by removing excess fluids and waste products, which are then excreted in the urine. Other key functions include keeping the body’s salts in balance and controlling red blood cell production and blood pressure.

**Types of childhood kidney tumour**

In the UK almost 1700 children are diagnosed with cancer each year. About 5% of these, or around 80-85 children, are diagnosed with kidney cancer. There are a number of different types of childhood kidney cancer but Wilms’ tumour is by far the most common.

About 90% of cases of kidney cancer in children are Wilms’ tumours. Malignant rhabdoid tumour of the kidney (MRTK) and clear cell sarcoma of the kidney (CCSK) each account for 3–4% of cases. Both of these cancers were initially thought to be higher risk variants of Wilms’ tumour but now it is known that they are different cancers.

**Most common types of kidney cancer**

The most common type of kidney cancer that occurs in adults is renal cell carcinoma, but this is hardly ever seen in children. Fewer than 2% of all childhood kidney cancers are renal cell carcinomas. If this type of cancer occurs in children, it is a different ‘subtype’ and has different features to the common adult renal cell carcinoma.

**Other childhood kidney cancers**

Other types of childhood kidney cancer are even more uncommon. Primitive neuroectodermal tumour (PNET) of the kidney accounts for just 1% of new cases. However, as it was only recognised as a distinct type of cancer in the 1990s, this percentage may be an underestimate.

Other types of childhood kidney cancer, including rhabdomyosarcoma of the kidney, desmoplastic small round cell tumours of the kidney, primary renal synovial sarcoma, and anaplastic sarcoma of the kidney, account for 2-3% of cases between them.
Proportion of childhood kidney cancers

In addition to malignant tumours, several types of benign (non-cancerous) kidney tumours also occur in childhood. The most common of these is mesoblastic nephroma. This is a usually benign tumour that is often diagnosed during pregnancy, when it is seen on an ultrasound scan. It is usually treated with surgery only.

Childhood kidney cancers:
- Wilms’ tumour: 90%
- Malignant rhabdoid tumour of the kidney: 3-4%
- Clear cell sarcoma: 3-4%
- Renal cell carcinoma: 2%
- Other types: 2%

5% of childhood cancers are kidney tumours.
Signs of childhood kidney tumours include a lump in the tummy, which can often be painless, blood in the urine (called haematuria) and fever. Children with kidney cancer may sometimes have signs and symptoms of high blood pressure (hypertension), such as headache, feeling tired (lethargy), chest pain, and problems with seeing or breathing. You should check with your child’s doctor if your child has any of these symptoms.

When a kidney cancer spreads (known as metastasis or stage 4 disease), this is usually to the lungs or liver. Metastases may only be picked up on x-rays or scans. Occasionally, they may cause a cough or trouble with breathing, or pain.

Most children are very well at diagnosis, and have very little in the way of symptoms. A tummy lump is often identified incidentally.

**Causes**

As with most childhood cancers, the causes of most childhood kidney cancers are unknown. It is not infectious and cannot be passed on to other people.

There are certain factors (risk factors) that increase the chance of kidney cancer occurring in some children, such as inherited (genetic) factors. These genetic risk factors are different depending on the type of kidney cancer. Genetic factors only account for a small number of children with kidney cancer.
Tests and scans

**Tumour biopsy**
A small piece of tumour is often taken for examination. This test is known as a biopsy. It involves an operation where your child has a general anaesthetic and a piece of the tumour is taken out through a small cut (incision) or needle puncture in the skin. A series of tests may be carried out on the cells in this biopsy to find out more about the biology of the tumour. Knowing about tumour biology provides information that is used in deciding the best treatment for your child.

**Blood tests**
Blood for testing may be taken from a vein in your child’s arm or by a finger prick. You are probably familiar with both of these procedures.

**X-rays**
X-ray images may be taken to investigate the location of the tumour and whether the tumour has spread.

**CT (computerised tomography) scans**
The CT scanner takes multiple x-ray images and these are converted by a computer to form a 3D view of either the whole body or of the part of the body under examination.

**Ultrasound scans**
Similarly to an ultrasound scan during pregnancy, the sound waves produced by the scanner bounce from solid organs inside the body and are recorded on a screen. The doctors can see the outlines or shadows of normal organs and of any tumour inside the body.
**Treatment**

The UK is an active member of the International Society for Paediatric Oncology (SIOP). In the UK, treatments for childhood kidney cancers are based on results of clinical trials performed by the SIOP Renal Tumours Study Group (SIOP-RTSG). This is a group of doctors from several countries who are experts in the specialist areas that are needed to treat children with kidney cancers. They work together to decide on the best treatments currently available and to design clinical trials that test new treatments or better ways to give treatments.

The course of treatment recommended for your child will be discussed with a **multi-disciplinary team (MDT)** at your main hospital. The MDT is a group of doctors and other health professionals with expertise in childhood cancer, who together discuss the best course of treatment for their patients. This team will include oncologists, surgeons, pathologists, radiologists and specialist nurses. Decisions about how to treat your child’s tumour will be determined by a number of factors including the specific cells that make up the tumour, the stage of the cancer, the type and size of the tumour, the age of the child, whether the tumour can be removed by surgery, the presence of genetic abnormalities, and whether the cancer is newly diagnosed or has recurred.

**MRI (magnetic resonance imaging) scans**

An MRI scan relies on magnetism and is a very safe procedure as no radiation is used. It takes longer than a CT scan and is quite noisy. There are no known side effects to this type of scan.

Apart from the need for an injection of ‘contrast’ during some CT scans, none of these investigations are painful to your child, but it is appreciated that they may feel unsettled or frightened. Some of the scans require that your child remains still for quite some time and to assist in this sedation may be given. An anaesthetist may be needed for some children to have some of the tests.

**It may take several days for any tests to be completed and the results analysed. Undergoing these tests and waiting for results can be a stressful time and lead to anxiety. However, exact assessment of the extent of your child’s disease before beginning treatment is very important. The results obtained will inform the type and length of treatment that will be given to your child.**
Wilms’ tumour

Wilms’ tumour (sometimes called nephroblastoma) is the most common type of kidney cancer in children. More than 90% kidney cancers in children are Wilms’ tumours.

Wilms’ tumour is almost always diagnosed in children under seven years old, and in 90% of cases it affects just one of the two kidneys (unilateral disease). Most cases of unilateral Wilms’ tumour occur at around three years of age, and it is more common in girls than boys.
Wilms’ tumour is an **embryonic kidney cancer** thought to develop from immature cells in the embryo. These cells are involved in the development of the kidneys while a child is in the womb, and usually disappear at birth. However, in many children with Wilms’ tumour, clusters of these cells can still be found.

It is not known what causes Wilms’ tumour but several risk factors have been identified. The development of Wilms’ tumour is thought to have at least partly a genetic cause and a number of genetic abnormalities and malformation syndromes are associated with developing Wilms’ tumour. A family history, though, is present in only 1–2% of cases, and therefore it is unlikely to be hereditary.

The outlook, or **prognosis**, for children with Wilms’ tumour is very good. In Europe and North America, the percentage of cases who survive for five years or more (**five-year survival**), is now over 85%.

**Diagnosis of Wilms’ tumour**

Diagnosis of Wilms’ tumour is mainly done through ultrasound, CT or MRI imaging. Imaging will determine if one or both kidneys are affected, whether there is a kidney abnormality (1–2% of patients with Wilms’ tumour have a fused horseshoe-shaped kidney), and the stage of the tumour. In the UK a biopsy (a small sample of the tumour) is usually taken so that doctors can confirm a diagnosis of Wilms’ tumour. The stage of the tumour, and how it looks under a microscope (**histology**) can help doctors plan the course of treatment needed.
Commonly used staging for Wilms’ tumour

**STAGE 1:** The tumour is only affecting the kidney and has not begun to spread. It can be completely removed with surgery.

**STAGE 2:** The tumour has begun to spread beyond the kidney to nearby structures, but it is still possible to remove it completely with surgery.

**STAGE 3:** The tumour has spread beyond the kidney; either because the tumour has burst before (or during) the operation, has spread to lymph glands (nodes), or has not been completely removed by surgery.

**STAGE 4:** The tumour has spread to other parts of the body such as the lungs or liver. Tumours in other parts of the body are known as metastases.

**STAGE 5:** There are tumours in both kidneys (bilateral Wilms’ tumour).

If the tumour comes back after initial treatment, this is known as recurrent or relapsed disease.
Treatment of Wilms’ tumour

Treatment for Wilms’ tumour will depend on the size of the cancer, if it has spread outside the kidney (stage) and the appearance down the microscope (histology). As Wilms’ tumours are rare, children with Wilms’ tumour are treated in specialist children’s cancer centres (Principal Treatment Centres) and treatment is planned by a multi-disciplinary team (MDT).

In the UK and the rest of Europe, treatment for Wilms’ tumour is based on guidelines developed by SIOP. Treatment typically consists of first treating your child with chemotherapy to shrink the tumour and make surgery easier, followed by an operation to remove the kidney containing the tumour (nephrectomy).

The type of chemotherapy that is needed after surgery and whether radiotherapy is also needed depends on the tumour histology and stage. An overview of the treatment pathway for Wilms’ tumour in the UK is shown below.

The number of drugs involved and length of chemotherapy before surgery depends on whether the disease has spread outside the kidney. After surgery the tissue removed by surgery is examined under a microscope to assess the effect of any pre-operative (given before surgery) chemotherapy and determine what treatment is needed after surgery. Based on the histology, the tumour is classified into three risk groups - low, intermediate and high.

- Most Wilms’ tumours fall into the intermediate risk group.
- Two types of Wilms’ tumour - called anaplastic and blastemal-type are considered high risk and require more intensive (stronger) chemotherapy

These risk groups help doctors to decide the best course of treatment. Some patients with higher risk tumours will go on to receive radiotherapy to the tumour, but also to the chest if there is evidence of the disease having spread at the time of diagnosis.

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<td>No evidence of tumour spread beyond the kidney (localised disease). Chemotherapy for 4-5 weeks with 2 drugs</td>
<td>Removal of whole kidney (called a nephrectomy).</td>
<td>Between 4 and 35 week course of chemotherapy (depending on the stage and histology of the tumour).</td>
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| Tumour spread outside kidney (stage 4). Chemotherapy for 6-7 weeks with 3 drugs. | Partial nephrectomy (if both kidneys have tumour). | Radiotherapy:  
  • Flank (between the ribs and the hip) only for tumours that are stage III or more  
  • Lungs only for metastases that are slow to respond or high risk histology. |
| Bilateral Wilms’ tumour (stage 5). Chemotherapy for 6-12 weeks with 2 or 3 drugs. | |  

Overview of treatment pathway for Wilms’ tumour in the UK
Bilateral Wilms’ tumour

Around 5% of children have Wilms’ tumour affecting both kidneys at the same time (bilateral Wilms’ tumour). Whilst it is still very possible to cure children with bilateral Wilms’ tumour, it poses additional challenges, particularly at the point of surgery.

The emphasis for these patients will be to give a longer chemotherapy course before surgery in order to get the maximum shrinkage of tumours on both sides prior to surgery. It is often possible to spare kidney tissue at the operation by performing ‘nephron sparing surgery’. This involves a great deal of discussion beforehand both at your child’s MDT and occasionally with the national CCLG Renal Tumour Group in the UK to decide on the best approach. It is very rare nowadays that children have to lose both kidneys and then require dialysis until a kidney transplant. Each child with bilateral Wilms’ tumour has a personalised treatment plan, aiming for the best possible prognosis in the long term.

Relapsed Wilms’ tumour

Most (more than 85%) of children with Wilms’ tumour are successfully treated. However for a small number of children the cancer will come back. Usually this happens after a period of time when the tumour could not be detected. This is known as tumour relapse. There are treatments available for relapsed Wilms’ tumour.

For more information about relapsed Wilms’ tumour, see the CCLG factsheet ‘My child’s Wilms’ tumour has come back’.
Clinical trials for Wilms’ tumour

The treatment for Wilms’ tumour is constantly being improved through clinical trials. Sometimes the best treatment choice for your child may be taking part in a clinical trial. If a clinical trial is suggested then you will be given information about what is involved.

Information about current clinical trials for Wilms’ tumour can be found on the Cancer Research UK webpage ‘Find a Clinical Trial’ and these can be discussed with your child’s doctor.

The CCLG factsheet ‘A guide to clinical trials’ is designed to help parents and young people understand more about clinical trials and answer some of the many questions that you may have about entry onto clinical trials.

Side effects of treatment

There are a number of possible side effects from treatment. These are usually short-term, lasting only while the treatment is given and depend on the drugs used. Some side effects can continue or only appear months or years after treatment and these are called late effects. The risks of any side effects of treatment will be carefully explained to you.

The chemotherapy drugs most often used to treat Wilms’ tumour are vincristine, actinomycin D and sometimes doxorubicin. All can have side effects that will be carefully explained. A serious side effect of actinomycin D is liver toxicity, but this occurs only rarely. A rare late effect of doxorubicin is cardiotoxicity (heart problems) which will be carefully explained.

CCLG publications are available free at hospitals treating children with cancer. They can also be downloaded and ordered from the CCLG website at www.cclg.org.uk/publications
Living with a single kidney

It is perfectly possible to lead a completely normal life with only one kidney, but it is important to look after your remaining kidney throughout your life. There are some very simple measures that can be taken to monitor that your one kidney is working well. This will include an annual blood pressure check and urine test to look at how well the kidney is at filtering waste from the body.

To keep your single kidney healthy you should drink plenty of fluid especially on a hot day and eat a healthy, balanced diet. You should not ignore symptoms that might be a urinary tract infection, for example fever, tummy ache and burning sensation while passing urine. If this occurs you should see your GP.

Regular exercise is very important. Some doctors have differing opinions on contact sports particularly as you get older in your teens and adulthood. Some doctors may advise body padding to avoid injuring the single kidney. Talk to your doctors before taking up competitive sports to discuss this further.

What happens after planned treatment is finished?

After planned treatment finishes your child will continue to be monitored and will receive follow-up care well into adult life. At the end of treatment each child will be given a personalised follow-up plan.

In general, from the date treatment finishes, your child will have an ultrasound scan of their abdomen (tummy) every 3 months for 2 years and regular chest x-rays every 3 months for 3 years.

At each clinic visit doctors will check your child’s blood pressure and urine and each year a blood test will check kidney function. If any of these tests are abnormal your child’s doctor may perform additional tests such as a CT scan, MRI scans or extra blood tests.

An annual check of blood pressure and protein in the urine is recommended for children with only one kidney for the rest of their lives. Blood tests to check kidney function can be done less often.

Children who were treated with the drug doxorubicin as part of their chemotherapy will need a special ultrasound scan of the heart (echocardiogram) every few years.

The CCLG website provides information about what happens after treatment and some help and advice for when your child finishes treatment. You can also find further information in the CCLG booklet ‘My child has finished treatment – what happens next?’.
Other childhood kidney tumours

Around 10% of childhood kidney tumours are not Wilms’ tumours, and this number is comprised of a variety of rare tumours.
Clear cell sarcoma of the kidney (CCSK)

Clear cell sarcoma of the kidney (CCSK) is an uncommon type of kidney cancer and makes up 3-4% of all kidney cancers in children. CCSK affects children at about the same age as Wilms’ tumour (around three years of age), and usually presents with the same types of symptoms (lump in the tummy, blood in the urine). It is not easy to tell the difference between the two types of tumour on imaging scans and diagnosis of CCSK is usually made from a biopsy of the tumour.

CCSK occurs more commonly in boys and the cancer sometimes spreads to the bones or brain, which is unusual in Wilms’ tumour. CCSK does not appear to be associated with malformation syndromes, and familial cases have not been reported. Survival from this type of kidney cancer is almost as good as for Wilms’ tumour provided stronger treatment is given.

CCSK treatment is similar to Wilms’ tumour and includes surgery, chemotherapy and radiotherapy. However all children will be treated with the drug doxorubicin as part of their chemotherapy regime and most patients (except stage I) will have post-operative radiotherapy. This is a rare type of cancer in children and treatment will be provided in a specialist children’s cancer centre with a treatment plan determined by a multidisciplinary team. If appropriate, children may be offered the opportunity to join a clinical trial.

About one in four children with CCSK will relapse and need additional treatment.

As for Wilms’ tumour and other childhood cancers, after treatment finishes, children will continue to be monitored and assessed and will receive follow-up care well into adult life. The follow-up tests for children with CCSK are largely the same as for children with Wilms’ tumour (abdominal ultrasound scans, chest x-ray, urine tests and blood tests). If the cancer has spread to other organs such as the brain or bones when the cancer was diagnosed, additional tests may be needed and these parts of the body may also be checked during follow-up.
Malignant rhabdoid tumour of the kidney (MRTK)

Malignant rhabdoid tumour of the kidney (MRTK) accounts for between 3 and 4% of all kidney tumours in children. While MRTK was first recognised in the kidney, it is now known to occur elsewhere in the body as well.

Children with this tumour are generally found by their doctor to have a detectable abdominal lump plus other signs, such as haematuria (blood in the urine), fever, infection, hypertension (high blood pressure) and anaemia (an abnormally low number of red blood cells). MRTK is found in younger children with two-thirds of children under 12 months old. Boys and girls are equally affected.

This tumour has a characteristic genetic change, and nearly all MRTK tumours have a mutation in a gene called INI1 (sometimes also called SMARCB1, BAF47, or hSNF5). There are rare families that carry a mutation in this gene, and sometimes in these families more than one case of this tumour has occurred. If your child has this type of tumour your doctor may discuss genetic screening for your family.

This tumour looks similar on imaging by ultrasound, CT or MRI to Wilms’ tumour, and diagnosis requires histological examination of a biopsy sample. In particular, the genetic alteration in the INI1 gene is characteristic of MRTK and does not occur in other cancers. Doctors can use this genetic alteration to confirm a diagnosis of MRTK.

MRTK is highly aggressive and progresses rapidly, often affecting both kidneys. About two-thirds of children have advanced disease when they are diagnosed. This is a rare type of cancer in children and treatment will be provided in a specialist children’s cancer centre with a treatment plan determined by a multidisciplinary team.

In the UK, MRTK is treated with intensive chemotherapy, surgery, and then chemotherapy again, in conjunction with radiotherapy. Even with such treatment, the outlook for patients with this disease is generally poor, although some children have experienced extensive responses.

New treatments for this cancer are being sought, and the best treatment option for your child would usually be to enter a clinical trial.

The CCLG website provides information and support for children and their families in understanding their diagnosis, treatment and what to expect now and in the future.
Renal cell carcinoma (RCC)

Renal cell carcinoma (RCC) is the most common form of kidney cancer in adults but it is rare in children younger than 15 years old. Many children with RCC have type of RCC called ‘translocation renal cell carcinoma’. This type is known to be caused by a specific genetic alteration involving a gene called TFE3 or TFEB. About 50-70% of children and young adults with RCCs have this alteration. Several other subtypes of renal cell carcinoma can be found in children and young adults.

The most common features found at diagnosis are pain, haematuria and an abdominal lump. Fever, weight loss and lethargy may also be seen. There are several genetic syndromes associated with RCC and your child’s doctor may check to see if your family might have one of these related syndromes and in some cases recommend genetic screening. Most children with RCC do well but overall prognosis is dependent on the stage of the tumour at diagnosis.

Treatment for children with RCC will be provided in a specialist children’s cancer centre with a treatment plan determined by a multi-disciplinary team. Surgery is the cornerstone of treatment for this type of kidney cancer. Many children with RCC require only surgery and have done well without chemotherapy, even if the disease had spread to the lymph nodes. In patients with metastatic cancer, some chemotherapy treatments, and a new type of drug that targets the abnormal proteins that results from changes in the tumour DNA, such as sunitinib, may be effective. As for other types of rare kidney cancers your child’s doctor may suggest that the best treatment option is for your child to be part of a clinical trial.

Mesoblastic nephroma

Mesoblastic nephroma is sometimes called congenital mesoblastic nephroma (CMN) because it may be present at birth but the average age of diagnosis is 3-4 months. CMN is very uncommon and from 1996 to 2005, only 42 cases were recorded in the UK. It is generally considered a benign (non-malignant) tumour but it may behave like a cancer in certain cases. The young children affected by mesoblastic nephroma often don’t have any symptoms, and a lump is detected during a routine examination. More and more cases are being discovered during the regular ultrasound scans done during pregnancy. In these cases, there is usually no rush for the baby to be born early, unless the tumour is causing strain on the heart because of increased blood flow through the tumour. Some older children with mesoblastic nephroma will have the same symptoms as a child with a Wilms’ tumour – lump in the tummy, hypertension, blood in the urine. There are two main subtypes of mesoblastic nephroma that are only
distinguished under the microscope: classic (or conventional) and cellular (or atypical). Cellular mesoblastic nephroma is typically distinguished by characteristic genetic change involving genes called ETV6 (TEL) and NTRK3. Classic disease tends to be found in very young babies or before birth, and cellular disease tends to be found in older infants. However, some patients show a mixture of the two types. Mesoblastic nephroma is usually treated with surgery only. This treatment usually leads to excellent outcomes, with 95% survival rates. Even if the tumour has started to spread, doctors will often choose not to treat with any other therapy. Notwithstanding this, the cellular subtype is known to respond to various combinations of chemotherapy.

Other very rare types of kidney cancer in children

There are other types of kidney cancer that have been described in children. Typically these tumours have been described in a limited number of children. Primitive neuroectodermal tumour (PNET) of the kidney is very rare, with only approximately 50 cases known to medicine. Primary renal synovial sarcoma of the kidney is also very rare, with fewer than 70 cases described since its characterisation in 1999. Anaplastic sarcoma of the kidney usually affects females and has a broad age range but has been documented in children. Rhabdomyosarcoma of the kidney is a rare soft-tissue sarcoma usually diagnosed in children around 6 years of age.

Treatment will depend on the type of cancer but typically will include surgery, chemotherapy and radiotherapy. If your child has one of these rare types of kidney cancers they will be treated in a specialist cancer centre and the MDT will determine the best treatment plan for your child. This may include participation in a clinical trial.
Coping with kidney tumours

Information and support for families whose child has a kidney tumour.
Talking to your child

One of the hardest parts of caring for a child with cancer is knowing what to say and how much information to give them.

Answering questions honestly is best. Some children may not ask questions, but this doesn’t mean they don’t want to know what’s happening. They may be frightened and uncertain of many things. Some children may even wonder if they have done something wrong and that’s why they have cancer.

You can ask your doctors or nurses for guidance on how to talk to your child. There are also booklets available from CCLG, CLIC Sargent and Macmillan Cancer Support that can help you explain the illness and treatment.

You can ask the doctors and nurses questions again if you’ve been unable to take it all in. It may help to write down your questions beforehand.

Coping with kidney tumours

Coping with tests

Whatever your child’s age, a truthful approach to what is happening is also needed when helping to prepare them for tests and investigations. It is very tempting to try and calm a frightened toddler by the reassurance that “….it won’t hurt…..”. If this is not true, your child may lose trust in you and feel very insecure. If you can, it is better to find something positive in a nasty situation. You may say, for example, “…Yes, this finger prick will hurt a bit just for a moment, but Mummy/Daddy will stay with you all the time and then we’ll go to the playroom/make a drink/read a story….etc.”. 
Asking your child to be a “big girl” or “brave boy” can be unhelpful when your child is frightened. Approaches such as “We will all shout ‘ouch’ together when the prick happens” can help your child to know that the adults appreciate that it hurts a bit and it isn’t shameful or babyish to cry.

Specialist members of the treatment team, such as the play specialist and school teacher, will have books, games and specially adapted toys to help familiarise your child with procedures used in their treatment, and to help them express their feelings through play. A favourite with young children is often the ‘hospital corner’ of the playroom or, for a child in bed, a bandaged teddy who receives more than his fair share of ‘injections’. This often incidentally helps your child to make sense of, and have some control over, what is happening to them.

You and your family

Having a child diagnosed with cancer will affect you as parents or carers, your other children, and the people close to you.

Understandably, you’ll feel worried and stressed as you come to terms with the diagnosis and what it means for your child to go through treatment. You’ll worry that your child will suffer and that your family life is going to be completely disrupted. At first, you may worry that your child is going to die.

You may be unable to hear or remember information about your child’s diagnosis or treatment. You may also feel overwhelmed by painful and powerful emotions. These reactions are normal – remember the doctors and nurses are there to help you at this time. There are also other people and organisations that can offer support (see page 34).

Seeking information

You may want to find out as much as possible about the cancer and its treatment. There’s a lot of information on the internet but not all of it is reliable, so talk to the doctors about where to look. The best advice is to use a website by a recognised organisation such as CCLG, Macmillan or Cancer Research UK.

Everyone is different – you may read about a child in a similar situation to yours, but they may have a very different experience. Remember, too, that statistics are only helpful to a degree. They’re based on large numbers of people and can’t say what will happen with your child in particular.

You can ask the doctors and nurses questions again if you’ve been unable to take it all in. It may help to have someone else with you, and to write down your questions beforehand.

CCLG produces a factsheet entitled ‘How can the internet help us?’

It gives tips on finding reliable and user-friendly information about cancer care and treatment on the internet.
Feelings and emotions

Some of the feelings and emotions you may have are described briefly below. Your feelings are likely to change over time and you may not experience all the emotions described here.

**Shock**

This is one of the most common feelings experienced when first faced with a cancer diagnosis. This is a completely normal reaction which can in the short term cause a range of physical and emotional symptoms such as lack of sleep, lack of appetite, nausea and anxiety.

**Fear and denial**

You may feel scared, anxious, and panicky about what’s going to happen and what the future holds. Understandably, parents often want to deny that such a terrible thing could happen to their child. Some people may feel tempted to take their child from one doctor to another. At times, you may feel the fear is almost too much to bear, such as when your child is going into the operating theatre and you wave goodbye.

**Sadness**

It’s natural to feel sad or depressed at times. Every parent wants their child to be healthy, happy and carefree. Cancer and its treatment can have a big impact on you and your child’s life. At times, you may have feelings of hopelessness. You may find it difficult to eat or sleep, or feel as though you have no energy for the things you need to do each day.

Parents often say that they feel overwhelmed by the enormity of the situation. These painful and unpleasant feelings can’t be avoided, and you’re likely to have them at various times during your child’s illness. It’s important to have support to help you through these times.

**Guilt**

It’s very common for a parent to feel guilty if their child has cancer. Some people wonder if it was something they did or didn’t do that caused the cancer, or they feel it’s a punishment for something they did in the past. Sometimes, parents blame themselves for not noticing their child’s symptoms quickly enough.

Many parents will have strong feelings of guilt, but it’s important to remember you’re not responsible for causing your child’s cancer.

**Anger**

It’s normal to feel angry at times. You may feel angry with the hospital staff for putting your child through tests and treatment. You may feel angry that you have to cope with such uncertainty, and the unfamiliar world of hospitals, doctors and nurses. Some people even find that they’re angry with their child, as it’s their illness that is causing so many problems for the family. This can be distressing but it’s also normal.

Parents can feel angry at each other, especially if they have different ways of coping with their child’s illness. For example, one parent might want to talk about it a lot and the other might just want to get on with normal life as much as possible.

You may also feel angry with family or friends who make thoughtless remarks or are too busy to give you support. Or you might feel frustrated with people who avoid you because they don’t know what to say.
Looking after yourself

It’s important to take care of your own needs and to not feel guilty about doing so. For example, eating and sleeping well, exercising if possible, dealing with any health problems and taking regular breaks will help you cope and care for your child.

Parents often find it hard to express their grief and fears to each other, with the result that they bottle up their feelings, become tense and quarrel more than usual.

Different people have different ways of coping with stress and what helps one can irritate another. If you can, try to talk to each other as openly as possible, and be as supportive and patient as you can.

You may find the following CCLG booklets helpful:

- Children and young people with cancer: A parent’s guide
- Family life and cancer
- Grandparents
- Helping brothers and sisters

If you can, try to talk to each other as openly as possible. Parents often find it hard to express their grief and fears to each other.
Brothers and sisters

The brothers and sisters of a child with cancer may have many or all of the same feelings and emotions that you have.

If you need to spend a lot of time in the hospital with your child, your other children may need to be cared for by family members or friends. They may have a lot of time away from you and find their daily routine keeps changing. As well as worrying about their brother or sister’s health, they may also feel resentful of all the attention they’re getting. This can make them feel very left out and angry. They may worry that they’re also going to get ill.

It can help to plan some time to let your other children be the centre of attention for a while, perhaps by going out for a meal or to see a film. Even 10 minutes at the end of a day can make a big difference. If your child with cancer is having some special attention – for example, having sweet treats or their favourite things to eat – you can do the same for other children in the family so they don’t feel left out.

The needs of brothers and sisters can sometimes be overlooked, particularly in the early months when you may spend most of your time caring for your ill child in hospital or at home. Many brothers and sisters keep their feelings bottled up inside to avoid worrying their parents.

Often, the place where siblings may show how they feel is at school. They may:
• withdraw and become very quiet
• become disruptive in the classroom
• cry easily
• become frustrated and have outbursts of anger
• fall behind in class work
• get lower marks than usual
• start missing school
• become rebellious towards teachers
• have arguments and fights with friends and other children in their class

It will help to let your children’s headteacher(s) know their brother or sister has been diagnosed with cancer. You can ask for the school’s help and support for your children. The teachers will understand that feelings may be expressed through behaviour at school, once they’re aware of the stresses facing the family.

If a sibling is obviously having difficulty dealing with the situation, talk about it with staff at the hospital such as the specialist nurses or the social worker. They can arrange for counselling, help and support for you and your other children. Some hospitals have support groups for siblings.
Going home

As soon as the diagnostic tests and first treatment cycles are over, you may be able to go home. Despite your obvious relief at being told you can leave hospital, and your pleasure at being reunited with the rest of your family, getting back to a normal routine may take a little time. Probably you have pinned a lot of hope on this as the time when your child will pick up, eat more normally again and temporarily forget about hospital.

All these things will hopefully be the case, but there may be some snags at first. There may be some sense of anti-climax as you and your child may have become ‘hospitalised’ to some extent.

You may find it difficult to sleep and eat normally at first. You may even, perhaps to your surprise, miss the company of other parents, the sharing of hospital routine and the security offered in the ward surroundings. Your child may be extra clingy and demanding just when you want to try and give more attention to other family members who have missed you.

Many parents who have previously been quite confident in their manner of caring for and bringing up their child find themselves worried and doubtful about applying even the most common sense rules.

The team at your child’s Principal Treatment Centre is still there to offer you advice and support. You may also find your GP and the community team an important source of support.

Behaviour

The question of discipline is a difficult one. Maintaining normal discipline is reassuring for your child and can help them feel secure.

Sleeping

If your child has had you by their side constantly in hospital, they may be more clingy at home or reluctant to sleep at first in their own bed again. However, it is usually best to remind them, as gently and firmly as possible, that home habits and hospital ones are separate and that at home they have their own cot or bed. At first your child may need to check your presence constantly by calling or coming into your room. Hopefully they will settle into the home routine again when they know you will not ‘give in’ and allow behaviour that was not allowed before their illness.

Eating

In the case of kidney tumours there are no particular restrictions on diet and usually no set medicine to take between hospital treatments*. Some parents have found that as treatment progresses the child does regain energy and appetite between or after each course of chemotherapy.

Eating is often an issue that causes concern to many parents. Your child may have lost weight, firstly because of the cancer itself and then because of the drugs that may have caused sickness and loss of appetite. Some children do not regain their former appetite or weight until the whole course of drug treatments has finished.

Unless your child’s doctor is worried about excessive weight loss it will
be considered fairly normal for them to remain rather thin throughout treatment. You may find it helpful to talk to the dietician at the hospital, who may be able to suggest ways of providing nourishing and weight building food. Sometimes supplementary feeding through a tube from the nose to the stomach, or even TPN (total parenteral nutrition) through the central line is needed.

*Some children’s treatment regimens, in particular children who need high risk chemotherapy and lung radiotherapy, result in an increased risk of infection, and these patients are given Septrin prophylaxis (precautionary antibiotics) which may be taken between hospital visits.

Reducing the risk of infection

It is very tempting to become overprotective of your ill child and perhaps of your healthy ones too in view of what has happened. You have probably been told by the treatment team to allow your child to do whatever they feel able, and it is very good to encourage them to regain their old skills and confidence as they feel better. Much of your desire to protect your child may be the result of medical advice to keep them away from sources of infection. Many parents agonise about the extent to which their child should mix with other children. You should follow the advice of your child’s doctor, but on the whole they should enjoy the benefits of mixing with others, with sensible precautions.

You will have been told measles and chickenpox are diseases your child should avoid if possible. Whilst this is not always easy, it helps to enlist your neighbours, friends, child’s teacher, possibly health visitor and your local doctor, to let you know if any child in your community has either got, or been in contact with, these infections. This also applies to the teachers of any of your other children. You cannot disrupt their schooling, but you should be extra cautious with your sick child if a brother or sister has measles or chickenpox in their class.

Even if your sick child does come into contact with measles or chickenpox there is no need to panic, but you must let a doctor know immediately. It may be possible to give your child a special injection in case of chickenpox, (called ‘ZIG’ which stands for Zoster Immune Globulin) either to reduce the attack or to prevent it completely. Some centres use an alternative drug called acyclovir instead of ZIG for this purpose. Zoster is the name of the chickenpox virus. It is identical to the virus causing shingles, which should also be avoided. If you have concern about possible contact, telephone the hospital or your doctor for advice.

If you think your child has been in contact with someone with measles or chickenpox, do not bring them to the hospital without first talking to your child’s medical team in case this spreads infection to other children.

You will also need to remember that your child should not receive the normal vaccinations while on chemotherapy. Always seek your doctor’s advice if your child is due for any kind of vaccination.
School

Children with cancer often have gaps in their education. This can be due to going into hospital, the side effects of treatment, or generally not feeling well enough to fully take part in daily school life. Most children’s cancer hospitals have education departments that can support your child while they’re in hospital. The teaching staff at the hospital will contact your child’s teachers to make sure they can continue their schooling whenever they feel well enough.

It’s even possible for children to take exams in hospital if necessary.

As your child’s health improves and if treatment allows, going back to school may be a relief or a challenge. For many children, school is a refuge from the world of hospitals and procedures – a place for fun, friends and learning. Going back to school can be a sign that life is returning to normal.

However, some children may dread going back to school. This may be because of temporary or permanent changes in their appearance.

Or they may worry that they’ll have missed a lot of work, or that being away will have affected their relationships with their friends.

Teachers have an important role to play in helping your child settle back into school, and helping other pupils understand what has happened to your child.

Keeping teachers informed

It’s important to let the school know how your child is doing. As soon as your child is diagnosed, contact the head teacher to tell them what’s happening. It can help to let the school know about the plans for treatment. The school teachers can then work with the hospital education department to make sure they cover the same work as the rest of the class. It can help for the teachers at the hospital to let the school know if your child is emotionally or physically fragile. The school teachers can then take this into account.

At any stage of treatment, your child should be involved in letting the teacher know what
information they would like to be shared with their classmates.

**Risk of infection at school**
For most children on cancer treatment returning to school is recommended, even when their immune system is low. It is important that they carry on with as normal a routine as possible. Most infections that children on cancer treatment pick up are not from other people or children. Chickenpox, measles or shingles can be dangerous to children who have a low immunity due to cancer treatment.

The school can develop a system to let other parents know that they should notify their child’s teacher if their child develops chickenpox, measles or shingles, so that appropriate action can be taken. If your child has been exposed to chickenpox and has not had it before, contact the hospital straight away. It may be necessary to give your child some medicine to prevent chickenpox developing.

It can be difficult to get the balance right between letting your child mix with their friends and worrying that they might pick up an infection.

You can discuss this with both the hospital staff and the teachers at school to make sure you’re happy with what your child does.

**Keeping up with schoolwork**
It’s important for your child to try to keep up with schoolwork whenever they can. Learning can continue outside school. By speaking regularly to the teacher, you’ll know which subjects are being covered. Often, the teacher will send assignments and materials home with siblings or arrangements can be made to collect them.

Your child should have an individual education plan in place. This plan can be shared between your child’s school and hospital school to ensure there is consistency in what is being taught. To help your child keep up in school, you may need to ask for a special education statement. This qualifies your child for extra help.

**Very young children**
Some children diagnosed with kidney cancers are very young and have not yet started school. As a parent, you may have to choose between having your child at nursery throughout treatment or keeping your child at home.

Keeping your child at home may mean they have less chance for social growth and development, but if they stay at nursery you may feel there’s a risk of infection. There is no right or wrong decision – it’s a personal choice for you to make. You may want to think about whether:

- your child is already settled at nursery or pre-school
- your child’s social needs can be met by siblings and/or other children outside of the nursery
- your child is well enough to attend nursery or pre-school
- your child has already had chickenpox

It may be useful for you to talk to your specialist nurse or social worker about nursery attendance and the support they can offer to help.

The CCLG booklet ‘Welcome back!’ is a guide for teachers helping children and young people returning to school after a diagnosis of cancer.
After treatment, and follow-up

Understandably, children who have been in hospital can often be difficult and demanding when they go home. Younger children may behave in a more childish way, whereas older children may be aggressive or jealous of their healthy brothers and sisters. Maintaining discipline and having their friends over to visit can help children get back into everyday life. While it’s often a relief to get to the end of treatment, you may find that you feel more anxious and worried now that you and your child are not attending the hospital so regularly. This is normal – all of a sudden you don’t have the immediate reassurance from the doctors and other staff.

You may also be worried that symptoms will return once treatment ends. Remember, the hospital staff are still there to help you and will understand your concerns. It’s important to contact them if you have any worries about your child’s health. Despite all the improvements in cancer treatment, sometimes it doesn’t work. In this case another treatment may be available, but this isn’t the case for all children.

There’s a lot of support for families when a cancer comes back. Further information is available from CCLG, Macmillan and CLIC Sargent.

The CCLG booklet for parents entitled ‘My child has finished treatment’ helps answer some of the questions and concerns that arise when a child finishes their cancer treatment.
If your child cannot be cured

Sadly, sometimes parents are faced with the devastating news that there are no more treatment options available for your child, which means a cure is now no longer possible.

The goal shifts from being able to cure your child’s disease to providing the best quality of life for your child and managing their symptoms. You and your child will be looked after by a specialist team with expertise in managing symptoms, providing emotional and practical help and support to the whole family.

Palliative care

Palliative care is the phase of treatment where cure is no longer possible, and is concerned with managing symptoms and quality of life.

Aims of palliative care services:

• To arrange services to meet the specific needs of your child and your whole family
• To manage symptoms promptly
• To provide care where you want it (as far as possible)
• To provide your whole family with as much support as you need
Useful organisations

Bethany’s Wish
www.bethanyswish.co.uk
Tel: 0247 767 2030
Email: bethanyswish@gmail.com

Bethany’s Wish is the UK Wilms’ tumour charity, dedicated to Bethany Polanco, who sadly lost her fight to Wilms’ tumour.

Bethany’s Wish aims to raise awareness of Wilms’ tumour and childhood cancer. We support families of children with Wilms’ tumour across the UK, and each child diagnosed with Wilms’ tumour is given a special “B’s Bravery Bear Pack”, complete with special surprises.

We aim to be a voice for children with cancer, promoting change, innovation and prioritising new drug development. We also raise funds to support research into Wilms’ tumour.

Bethany’s Wish also supports families with any type of childhood cancer in their local area, Coventry and Warwickshire, and runs a support group (CROCCS) for parents and carers.

Action for Sick Children
www.actionforsickchildren.org
Helpline: 0800 074 4519
Provides advice and information for parents with children going to hospital. Offers counselling for parents and has leaflets and videos for children.

CCLG is the professional association for those involved in the treatment and care of children with cancer in the UK and Ireland. Through a network of Principal Treatment Centres, CCLG members together with other professionals are responsible for organising cancer treatment for children in the UK and are dedicated to improving best practice and outcomes.

CCLG is also a registered charity, providing high quality, award-winning information about childhood cancer to patients and families. We also fund and support research into childhood cancer.

Cancer Research UK
www.cancerresearchuk.org
Information on all cancer types and a key funder of research into cancer.

CLIC Sargent
www.clicsargent.org.uk
Provides practical support and advice for children and young people affected by childhood cancer and their families and offers accredited information for patients.

Macmillan Cancer Support
www.macmillan.org.uk
Provides practical medical and financial support to anyone who is affected by cancer.
Glossary

Alopecia: Loss of hair

Anaesthetic: Drug which stops feeling, especially pain. A general anaesthetic makes you unconscious. A local anaesthetic stops feeling in one part of the body.

Anaplastic Wilms’ tumour: About 5-10% of Wilms’ tumours have an appearance called anaplasia, which means the cells look very disorganised under a microscope. Considered to be a ‘higher risk’ type of Wilms’ tumour.

Bilateral: Affecting both kidneys

Biopsy: Removal of a small piece of tissue for examination, to establish a diagnosis.

Blastemal-type Wilms’ tumour: This group of high-risk tumours cannot be identified by looking at the biopsy because they occur when a particular type of early kidney cell survives the pre-surgery chemotherapy. These cells are known as blastemal cells. Tumours where most of these cells survive chemotherapy are called blastemal tumours.

Bone marrow: The substance at the centre of long bones that makes blood cells

Catheter: Tube passed into the body to drain fluid

Central line: (Hickman line, Port-a-cath) Long plastic tube that is inserted into a large vein near the heart under anaesthetic. Central lines are used to take blood samples and give drugs.

Chemotherapy: Treatment using one or more anti-cancer drugs

CT scan: Computerised Tomography scan. Multiple x-rays are taken by a CT scanner and converted by a computer to form a 3D view of the part of the body under examination

Genetic: A condition caused by abnormal genes (may be inherited)

Familial: A history of the disease in the family

Haematuria: Blood in the urine

Histology: The appearance of tissue under a microscope, which helps to determine the diagnosis

Immune system: The body’s defence against infection, disease and foreign substances

Immunology: The study of the body’s immune system, which fights infection

Immunosuppressive: Lowering the body’s ability to fight infection

Intravenous (IV): Into a vein, for example, when drugs are given directly through a drip

Malformation syndromes: Very rarely, people who develop Wilms’ tumour have other specific conditions which are present at birth (congenital malformations). These include the lack of an iris in the eye (aniridia), abnormalities of the genitals, and a condition where one side of the body is slightly larger than the other (hemihypertrophy).

Malignant: Cancerous

MDT: Multi-disciplinary team. A group of doctors and other health professionals with expertise in childhood cancer, who together discuss the best course of treatment for their patients.

Metastases: Cancer that has spread from the place where it started (also known as secondary cancer)

Nausea: Feeling sick

Nephrectomy: Surgery to completely remove a kidney

Nephroblastoma: Another name for Wilms’ tumour

Neutropenia or neutropenic: Low levels of neutrophils, a type of white blood cell which fights infection

Oncologist: A doctor who specialises in the treatment of cancer

Oncology: The study and treatment of cancer

Paediatric: To do with children

Palliative: Relief of a symptom (for example, pain) rather than cure of the disease

Prognosis: The outlook or expected outcome of a disease and its treatment

Radiotherapy: The use of radiation to treat cancer

Refractory: Resistant to treatment

Relapse: The return of symptoms of a disease after a period of good health; recurrence of a tumour after treatment

Remission: A period of good health where there is no longer any visible cancer

Surgery: An operation

Stem cell: Early (immature) blood cell from which other blood cells are made

Therapy: Treatment

Tumour: An abnormal lump of tissue formed by a collection of cells. It may be benign (non-cancerous) or malignant (cancerous)

Ultrasound scans: The sound waves produced by a scanner bounce from solid organs inside the body and are recorded on a screen. Allows doctors to see the outlines or shadows of normal organs and tumours.

Unilateral: Affecting one kidney only
Children’s Cancer and Leukaemia Group is a leading children’s cancer charity and the UK and Ireland’s professional association for those involved in the treatment and care of children with cancer. Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Two out of ten children will not survive their disease.

We bring together childhood cancer professionals to ensure all children receive the best possible treatment and care. We fund and support research into childhood cancers, and we help young patients and their families with our expert, high quality and award-winning information resources.

If you have any comments on this booklet please contact us at the address below

CCLG publications on a variety of topics related to children’s cancer are available to order or download free of charge from our website

Children’s Cancer and Leukaemia Group
University of Leicester
Clinical Sciences Building
Leicester Royal Infirmary
Leicester LE2 7LX

Registered Charity number 286669

Bethany’s Wish is a UK charity dedicated to Bethany Polanco, who sadly lost her fight to Wilms’ tumour, a rare childhood cancer of the kidney. Bethany’s Wish raises awareness of Wilms’ and childhood cancer, supports other families still fighting and raises funds for research into Wilms’ tumours.

Bethany’s Wish
Floor 14, Coventry Point,
17 Market Way, Coventry
CV1 1EA

Registered Charity number 1151760