

**A booklet for parents**

What you need to know

# Rhabdomyosarcoma

[www.rhabdomyosarcomabooklet.org.uk](http://www.rhabdomyosarcomabooklet.org.uk)

Updated April 2012



Dedicated to Dr Jon Pritchard who believed passionately in the role parents and families could play as part of the caring team.

## **ABOUT THIS BOOKLET**

01 About This Booklet

### **SECTION 1:**

#### **RHABDOMYOSARCOMA – THE FACTS**

06 What is Cancer?

06 What is Rhabdomyosarcoma?

09 Diagnosis and Treatment

09 Diagnosis

11 Staging

13 Treatment

15 Treatment Centres

15 Clinical Trials

### **SECTION 2:**

#### **COPING WITH RHABDOMYOSARCOMA**

18 Diagnosis and Start of Treatment

18 Your Diagnosis

20 Communication

23 Understanding the Protocol

24 Central Line Decision

26 Chemotherapy and its Immediate Side Effects

28 Effects on the Blood and the Immune System

30 Longer Term Effects of Treatment

35 'On the Treadmill'

35 Hospital Stays

38 Temperature Chart

39 Blood Count Results

40 Side-effects of Chemotherapy as Treatment

Progresses

40 School and Activities

42 Food and Nutrition

43 Surgery

44 Radiotherapy

46 Communication

47 Siblings

48 Positive Thinking

49 Complementary (Alternative) Therapy

50 End of Treatment

### **SECTION 3:**

#### **REFERENCE**

54 The Medical Team

57 Glossary of Terms

64 Helpful References

## ABOUT THIS BOOKLET



Claire, aged 7 years, on the right, with her brother Alexander. This booklet was written by Dianne Haley whose daughter Claire was diagnosed and treated for rhabdomyosarcoma in 2004/5. Professional advice was provided by Dr Jon Pritchard, Dr Hamish Wallace, Sister Caroline Rose and the team at the Royal Hospital for Sick Children and The Western General Hospital in Edinburgh.

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## **ABOUT THIS BOOKLET**

If you have been told recently that your child is suffering from rhabdomyosarcoma you will be feeling bewildered, frightened and shocked. You might not know much about cancer as a group of diseases and are trying to link what you do know to your child's condition. It is very important that you rely on the information given to you by your consultant and his or her team. Try not to be overly distracted by what other people tell you.

Cancer is a word that covers a huge range of conditions which differ in cause, treatment and cure. It is important that you try to focus on your own child and the facts of his or her particular situation.

## ABOUT THIS BOOKLET

You will receive so much new information at the time of diagnosis that it is impossible to take it all in. This booklet enables you to proceed one step at a time and aims to cover most of the issues which might come up at different points during your child's treatment.

It cannot answer specific questions about your child's particular tumour or treatment plan. The individual discussions with your consultant and medical team will provide you with that information. Your child's age and how much they – and their siblings – are able to understand about their illness will also have a big impact on how you deal with the issues which arise.

### **SECTION 1: RHABDOMYOSARCOMA THE FACTS**

Contains the most important facts about rhabdomyosarcoma.

### **SECTION 2: COPING WITH RHABDOMYOSARCOMA**

Concentrates on the practical ways of coping with rhabdomyosarcoma. This section is split between the start, middle and end of treatment.

### **SECTION 3: REFERENCE**

Contains the definitions of many medical words associated with rhabdomyosarcoma, explanations of the roles of the people you will meet at the hospital and some useful website addresses for further information.

## ABOUT THIS BOOKLET



Note pages are indicated using this icon.

There are pages for you to make notes at the end of each section of the booklet. It's a good idea to write down things that you especially want to know, so that you can raise them when you see different members of your medical and nursing team.

Having lists of questions – and writing down answers at the time – can help to act as a reminder for what you really want to ask and what you need to remember about your child's treatment. You will find as you get into the routine of being in hospital that some queries can be dealt with on the spot while others may need a setting and time when unhurried discussion can take place.

Diagnosis and treatment of rhabdomyosarcoma is something which the whole family, not only your child, goes through. There are many practical things that you and your family can do to help everyone come out as 'whole' as possible at the end of what will be many months of treatment and time spent in and out of hospital.

## **SECTION 1**

### RHABDOMYOSARCOMA THE FACTS

What is Cancer?

What is Rhabdomyosarcoma?

Diagnosis and Treatment



## **What is Cancer?**

Cancer occurs when cells in the body go out of control and multiply. They stop working properly and as their numbers increase they form a lump or tumour. When cancer cells break away and spread to other parts of the body, they may produce secondary tumours known as metastases.

## **What is Rhabdomyosarcoma?**

The word comes from Greek words meaning:

**rhabdo** – striped

**myo** – muscle

**sarcoma** – soft tissue tumour

Cancer in children is rare and its incidence (frequency) is not rising. Only 1 in 600 children under 15 years of age ever develops a cancer.

Sarcomas are rare types of cancer that develop in the bone, muscle or cartilage. Soft tissue sarcomas can develop in muscle, fat, blood vessels or in any of the other tissues that support, surround and protect the organs of the body. Bone sarcomas can develop in any of the bones of the skeleton but very similar tumours may also develop in the soft tissue near bones. The originating tumour is called the primary tumour and any tumours identified elsewhere are secondary tumours.

In children, rhabdomyosarcoma (often called rhabdo, for short) is the most common of the soft tissue sarcomas. These tumours develop from muscle or fibrous tissue often known as 'connective tissues' and can grow in almost any part of the body.

## SECTION 1

### RHABDOMYOSARCOMA THE FACTS

The most common areas are around the head and neck, the pelvic organs (bladder, prostate, vagina, uterus, peri-anal area) or near the testes. Sometimes the tumours are found in a muscle in a limb or in the chest or abdominal wall. Occasionally, if the tumour is in the head or neck region, it can spread into the brain or the fluid around the spinal cord.

The two major sub-types of rhabdomyosarcoma – the ‘embryonal’ type (about 75% of cases) and the ‘alveolar’ type (most of the others) are diagnosed by expert pathologists through microscope analysis. Of these two types, alveolar is the more aggressive.

The cause of rhabdomyosarcoma is understood in only a few cases. Research is going on all the time into possible causes of this disease and other risk factors that can contribute towards rhabdomyosarcoma and other cancers developing in children. There are no known environmental causes for rhabdomyosarcoma.

Most rhabdomyosarcomas appear out of the blue – a chance, unfortunate occurrence (around 95%) but in around 5% of cases a so-called predisposition gene may have been inherited from either the child’s mother or father. All of us pass on faulty genes to our children as well as good genes. Most ‘genetic faults’ don’t matter because the affected cells are eliminated by the body.

## SECTION 1

### RHABDOMYOSARCOMA THE FACTS

If your child's consultant feels that the pattern of your family tree suggests that an inherited gene may be involved, he or she will refer your family to a Clinical Geneticist in your area who specialises in cancer. The Clinical Geneticist will decide whether or not family blood tests are needed, will arrange to analyse the blood samples and, later, discuss the results and other implications with you.

The prognosis for children with rhabdomyosarcoma has improved dramatically over the last thirty years with overall survival rates of around 70% in 2000 (higher for the embryonal type and lower for the alveolar type). Overall survivability depends on a variety of factors, such as location of primary tumour, extent of spread, primary tumour size and age of child as well as on the sub-type.

There are about 50-100 new cases of rhabdomyosarcoma diagnosed in the UK each year – approximately two-thirds of all non-bone sarcomas in children aged 0-14 years. Statistics show that rhabdomyosarcoma has remained at this level for many years.

## **Diagnosis and Treatment**

### **Diagnosis**

The signs and symptoms of rhabdomyosarcoma will depend on the part of the body that is affected. The most common sign is an unexplained and painless swelling or lump.

If the tumour is in the head area it can make one of the eyes appear swollen and protruding or cause blockage and a discharge from the nose, throat or ear canal. If the tumour is in the abdomen the child may have discomfort in the abdomen and problems going to the toilet, either to pee or pass stools or both. A swelling may appear in the perineum (private parts). On the trunk or limbs, a painless swelling is the commonest early sign. Occasionally, tumours can appear inflamed rather like an infection or abscess.

A number of tests are undertaken to make a firm diagnosis of rhabdomyosarcoma. This will usually include a biopsy, which involves a small operation under a general anaesthetic to remove a sample from the tumour to be looked at under a microscope by an expert pathologist. Your child will probably also have a chest x-ray to check the lungs, an ultrasound scan, CT or MRI scans and blood and bone marrow tests. They may also have a PET scan, although only a few hospitals currently have these imaging machines. All the tests undertaken will give your consultant as complete a picture as possible of your child's tumour. More information on each type of test is provided below.

### **X-Ray**

You are probably familiar with ordinary x-rays.

### **CT Scan**

The CT (Computerised Tomography) scanner takes multiple x-ray films and these are 'converted' by a computer into a 3D view of part of the body.

## SECTION 1

### RHABDOMYOSARCOMA THE FACTS

#### Ultrasound Scan

You will be aware of the ultrasound scan from the tests done during pregnancy. The ultrasound scan works by passing a sonar over the surface of the child's body. The sound waves produced by the sonar 'bounce' from solid organs inside the body and are recorded on a screen. The screen shows the outlines or shadows of normal organs and of any tumour inside the body.



Ultrasound Scanning Machine.

#### MRI Scan

An MRI (Magnetic Resonance Imaging) scan relies on magnetism to take pictures of the body. An MRI scan usually takes longer than a CT scan and is quite noisy. It is important to keep very still during the scan and very small children are usually given a general anaesthetic.



MRI Scanning Machine.

Courtesy of Medical Photography, NHS Lothian

## SECTION 1

# RHABDOMYOSARCOMA THE FACTS

### **Bone Scan**

An (isotope) bone scan involves an injection of a small amount of a radioactive isotope into a vein. The radioactive material gathers in any bones to which the tumour has spread and may be seen when pictures are taken on a gamma camera.

### **Bone Marrow**

To examine the bone marrow for tumour cells, a needle is inserted into one of the larger bones (usually the hip bone) and a small quantity of bone marrow, found at the centre of the bone, is drawn out. This is called an 'aspirate'. A 'trephine' involves taking a sample at the core of the bone marrow. Aspirates and trephines may be taken from more than one site on any one occasion. The child will usually be given a general anaesthetic before these tests are carried out.

## **Staging**

Staging is the term used to describe the size of the primary tumour and whether it has spread beyond its site of origin, either into surrounding tissues or elsewhere in the body. This also helps the consultant to plan the specific treatment for your child.

There are different names and descriptions for staging in rhabdomyosarcoma, but a simple way of thinking of staging is as follows:

### **Stage 1**

The tumour can be removed in its entirety and lymph nodes are negative for tumour. There are no detectable secondary tumours (metastases) but it is still possible that tiny numbers of cancer cells have escaped into the blood stream and settled into other parts of the body. These are undetectable by any available type of scan and the reason that chemotherapy is required in every case of rhabdomyosarcoma.

## SECTION 1

### RHABDOMYOSARCOMA THE FACTS

#### **Stage 2**

The tumour was removed but, under the microscope, a little remains at the surgical margin, i.e. where the surgeon cut through apparently normal tissue. Any lymph nodes are negative and there are no metastases.

#### **Stage 3**

There are several categories of stage 3 rhabdomyosarcoma:

- (i) Because of its location – i.e. orbit or near the eye, bladder, uterus/vagina; middle ear or perineum – surgical resection would be too damaging so chemotherapy is used first to shrink the tumour as much as possible.
- (ii) Because of its location – i.e. back of nose, middle ear – the tumour cannot be removed without an unacceptable risk.
- (iii) Positive lymph nodes.

#### **Stage 4**

There are detectable metastatic tumour deposits in lungs, liver, brain, bone or bone marrow. Stage 4 is more common with the alveolar than with the embryonal type of rhabdomyosarcoma.

Once a firm diagnosis is made and the stage has been determined your consultant will decide on the protocol to be followed for your child's treatment. Protocol means a plan for the particular mix and timing of chemotherapy, radiotherapy and surgery.

Agreed national or international protocols are now followed for almost all childhood cancers and the most appropriate one for your child's tumour will be proposed. If you are confused about the stage of your child's tumour, you should ask your consultant to explain.

## SECTION 1

# RHABDOMYOSARCOMA THE FACTS

### Treatment

Most protocols for rhabdomyosarcoma combine a three-pronged approach: chemotherapy, radiotherapy and surgery. This is particularly important for the primary tumour. Some patients need all of these treatments whilst others only need one or two, keeping the other treatments in reserve. Each protocol is adapted to the needs of each individual child. The principles of these treatments are:



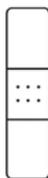
#### **Chemotherapy**

The use of drugs to destroy the cancer cells. Your child will probably need a combination of several different drugs to treat his or her tumour. Chemotherapy works on the whole body and attacks malignant cells wherever they are. More specifically, it persuades cancer cells to die, by altering their genetic programme. It also affects healthy cells, although healthy cells are constantly being replaced so the chemotherapy damages and destroys more cancer cells than normal cells. The management of side effects during the treatment is a major part of the care your child will receive.



#### **Radiotherapy**

The use of radiation treatment (high energy rays) which destroys cancer cells while doing as little harm as possible to normal cells. Radiotherapy is a highly targeted treatment on specific areas of the body. There are potential longer term side effects of the radiotherapy treatment, different to that of chemotherapy, which your consultant will explain to you.



#### **Surgery**

Surgery plays an important part in the treatment of tumours. In some cases it is fairly straightforward to remove the bulk of the tumour while in others, where the tumour might be close or attached to other organs, it isn't so easy. Your consultant will work closely with surgical colleagues to decide the best time for any operation.

Surgery will be used to remove the primary tumour and sometimes secondary tumours if they can all – or nearly all – be removed without leading to unacceptable long term disability for your child.

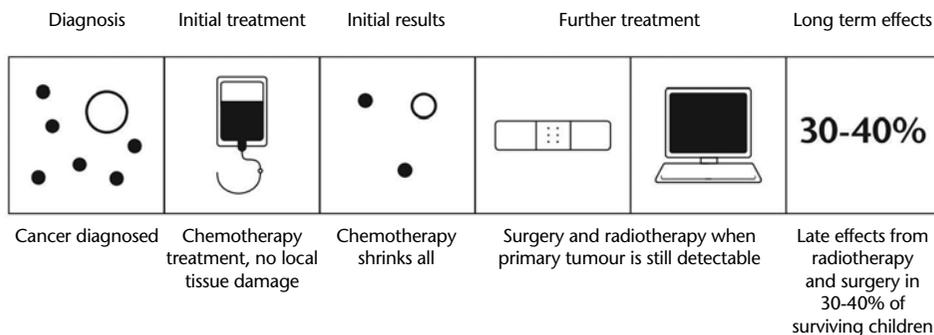
A sample protocol is shown on page 22.

## SECTION 1

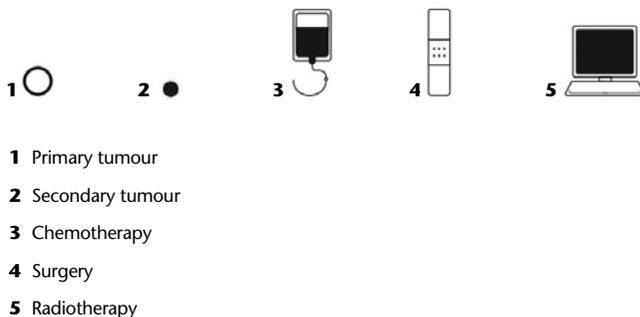
### RHABDOMYOSARCOMA THE FACTS

Before 1985, surgery was carried out first, with chemotherapy treatment following. Since then, chemotherapy has been given before surgery to shrink the tumour. Further cycles of chemotherapy and radiotherapy are then given to destroy any remaining malignant cells. The change in treatment approach over the last 30 years has led to a significant reduction in long term effects for children.

#### Current Treatment Approach



Key:



## SECTION 1

# RHABDOMYOSARCOMA THE FACTS

**Treatment Centres** There are 21 hospitals in the UK and Republic of Ireland which are specialised centres for the diagnosis and treatment of children's cancer. To make things a bit easier for your family you may receive some treatment in a local hospital near your home (shared care), but the overall management plan for your child's treatment will ultimately be undertaken from your closest centre. Specialist outreach nurses are important figures in shared care, linking the activities of the centre with your local hospital.

**Clinical Trials** The CCLG (Children's Cancer and Leukaemia Group) links together all 21 treatment centres in the UK and Eire. Together, and in an increasing number of cases with centres in other countries, they join up to try to improve the prognosis of rhabdomyosarcoma or lessen the side effects, especially the long term effects, of treatment. These multi-centre studies are usually termed clinical trials. What usually happens is that the better treatment from the previous trial – often known as the 'best standard treatment' – is taken forward to the next trial and compared with a new treatment. The good -and still improving - cure rate for children with rhabdomyosarcoma is due to a succession of clinical trials dating from the 1970s.

If you are concerned about your child being part of any trial or don't know why he or she is not part of a trial, please ask your consultant.



## **SECTION 2**

### **COPING WITH RHABDOMYOSARCOMA**

Diagnosis and Start of Treatment

'On the Treadmill'

End of Treatment



## Diagnosis and Start of Treatment

**Your Diagnosis** As your child progresses through detailed examinations to scans to a biopsy you will have become more and more worried that there is a serious problem. You will have several appointments arranged at short notice, often jumping the queue as an emergency case. A paediatric oncology consultant will appear early in this process. Although it may seem very rushed and frightening, all the doctors undertaking the tests are very keen to end the uncertainty and worry you are feeling and are striving to obtain a definite diagnosis as quickly as possible.

The key test for the diagnosis of rhabdomyosarcoma is the biopsy and you will probably wait a week or so for the pathologist's report. You will then have a meeting with the consultant oncologist or surgeon for them to tell you the diagnosis.

The news that your child has rhabdomyosarcoma is not what you wanted to hear and you will be shocked, worried and fearful. The consultant and senior nurses are there to help you through this very difficult time and to plan with you the treatment your child will need.

It is very likely at this stage that you will not take in much of the information you are given. You will be in shock and it is difficult to function as you normally would. Don't worry if you have not asked any of the questions you meant to. You will have plenty of opportunities to do so later. Quite often, parents feel overwhelmed by the enormity of what has happened and cannot deal with anything else at this time.

People deal with bad news in different ways. Over the first few days, it is important that you give your spouse, partner, close friends or family members space to get used to the news in his or her own way.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

As parents, being able to have even a few hours alone together to get used to the news and to talk about what has happened before starting to tell everyone else can be very helpful. If you are a single parent dealing with this news, it is important to have a close friend or family member with whom you can share your worries and fears.

You might be worried that you didn't spot your child's lump earlier or take action more quickly about any other symptoms. Try not to dwell on this. It is often the case that it is people outside the immediate family who notice new lumps or bumps in children. They don't see your child every day and are therefore more liable to notice when things change.

It is probable that your child's treatment will begin quite quickly after diagnosis. Although you will be worried about the treatment and its side-effects, it is important to start treatment promptly. Once the initial shock has faded, you may well be impatient for the doctors to start to deal with your child's tumour, however worried you may feel about the effects of the treatment on him or her.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

**Communication** The first issue to hit you is what to tell your child, his or her siblings and your wider family.

A child of any age will notice a tense atmosphere and hushed conversations. It is very important that your child learns about their own disease at the beginning from you – his or her trusted parents with the correct information – rather than hearing inaccurate things, from other people, that may frighten him or her.

What you actually say to your child and his or her siblings will depend on their age. For younger children, it may be enough at the start just to say something like... “Claire will need some strong medicine to take away her lump and will be in hospital for a few days each month.” For younger children of school age, it is also worth introducing the words that they might hear later, such as tumour or cancer, and explaining that these are just other words for their lump. At the start, you may want to protect your child from hearing the word cancer but it is inevitable that others will say it, particularly when your child loses his or her hair. So it is as well to talk about it yourself first.

For older children, they will want to know all that you know about their illness and may well have been with you when you were told the diagnosis. Being open and honest with them and talking together with the consultant about their questions will help you all to deal with the diagnosis. It may also be helpful for them to talk privately about their worries with members of the medical team, such as the doctor, social worker or psychologist.

Remember that older children may well have sufficient maturity to make decisions for themselves. You need to involve them as much as you think is right in making decisions about their treatment.

For all children, keeping life as normal as possible is very important. This means carrying on doing what you normally do as a family as far as you possibly can. This probably also means hiding your own doubts and worries from them to help maintain the stability of your home environment during a period of great change to your day to day lives.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

Telling close family members about the diagnosis is not easy and it often helps to tell one member of the family and ask them to tell everyone else. With friends, too, it is often worth calling a few close friends and asking them to pass on the news.

As soon as you can, you should see the headmaster or headmistress at your child's school to tell them about the diagnosis. You could also write to him or her with the facts about your child's illness and ask that they pass the information on to other members of staff and the parents of your child's classmates. Once this has happened, you could ask a parent in your child's class to pass on information to other parents on your child's progress. This is particularly helpful at the start of treatment when many people have lots of questions and someone else is able to deal with them.

After a week or so, an outreach nurse from the hospital will offer to meet with your child's headteacher and/or class teacher to give more information about rhabdomyosarcoma. This is a very important meeting, since your child will probably be attending school between their chemotherapy cycles and you will rely on school staff to recognise when they are too tired or ill to remain at school.

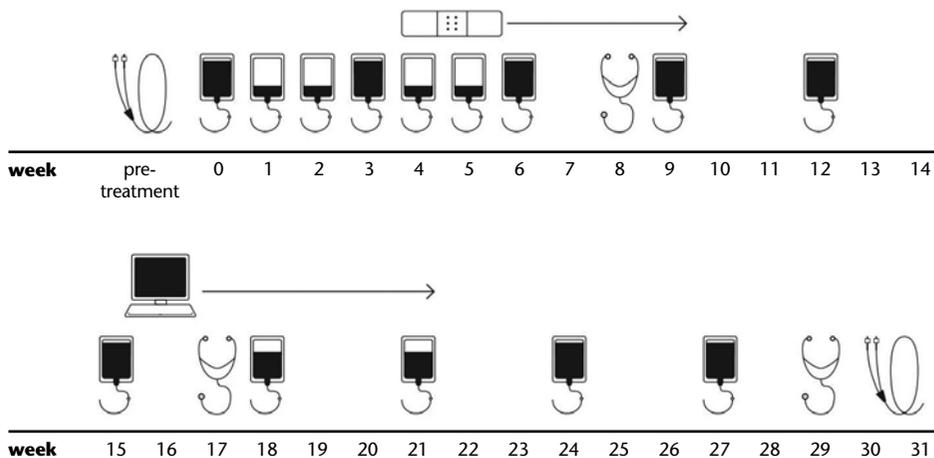
Communicating with others takes a huge amount of time when you have just received a diagnosis of rhabdomyosarcoma. You have too much to think about at the start of treatment to deal with all the reactions from your friends and neighbours, so try to use others to field the questions and concerns.

Despite your best efforts, you will find that the telephone rings constantly. Don't be afraid to use the answer phone. Let people leave messages and call them back if and when you want to.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

#### Example of a Simple Protocol



Key:



- 1 Central line insertion/removal
- 2 Chemotherapy (3-4 types)
- 3 Chemotherapy (2 types - some drugs may not be given during radiotherapy)
- 4 Chemotherapy (1 type)
- 5 Surgery
- 6 Assessment
- 7 Radiotherapy

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

#### **Understanding the Protocol**

Your consultant will have explained the treatment plan, called the protocol. This is a plan for the best combination of chemotherapy, radiotherapy and surgery for your child. The protocol shows the frequency of chemotherapy, the length of any radiotherapy that is needed and the likely timing of surgery. It will tell you how long the whole treatment plan is expected to take, usually between 5-12 months. There is likely to be a major assessment of progress including repeat scans with your consultant every 2-3 months or at significant points in the treatment plan, such as just prior to surgery or radiotherapy. An example of a simple protocol is shown in the diagram opposite.

Don't worry if you can't take in all the information in the protocol. Knowing when it is likely to start, the frequency of planned chemotherapy treatments and how long the whole treatment plan will probably take is enough to begin with.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

#### Central Line Decision

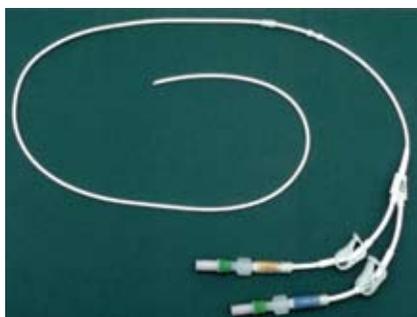
One of the first decisions that has to be made is what kind of central line your child should have. This is a tube inserted and tunnelled under the skin into a vein in such a way that allows treatment, including chemotherapy and other drugs, to be given easily and painlessly because it avoids the difficulty of inserting needles into small veins in the hand each time drugs need to be administered. The central line is put in under general anaesthetic and will stay in place until the end of your child's treatment.

There are two main types of central line: Hickman Line and Portacath. The type of central line which your child receives depends on several factors, including age, type of tumour and the chemotherapy he or she will receive.

#### Hickman Line

This line is inserted into the vein and brought out through the chest wall where it is secured at the 'exit site' by a stitch. When the line is not in use, the external part is secured in a special bag or with tape to prevent pulling and discomfort.

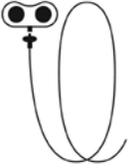
The Hickman line requires a dressing which needs to be changed weekly and the exit site cleaned. The line requires regular flushing when not in use. It is important that the cotton pouch holding the lines is washed 2-3 times a week to minimise risk of infection.



Hickman lines are often used when intensive therapy is required or if a child has needle phobia. Children with this type of central line are usually not permitted to go swimming and have to bathe or shower with care because of the risk of infection entering the line or exit site from the water.

## SECTION 2

# COPING WITH RHABDOMYOSARCOMA



### **Portacath**

This is a chamber with a silicone membrane which is placed surgically under the skin on the chest and has a tube leading into a vein. When not in use the 'Port' lies completely under the skin and has no external parts.

In order to use the Port a special hollow needle called a 'Gripper' is inserted through the skin into the chamber. A double Portacath may be used if two Gripper needles need to be inserted to administer two different types of fluid. Anaesthetic cream (magic cream) is applied at least an hour beforehand to ensure the 'Grippers' do not hurt when they are inserted through the skin.

When there is no Gripper in the Portacath your child can go swimming and have showers.



Your medical team will advise you whether there are any reasons why your child should have one type of central line or another. If you have a free choice and your child is not too scared of needles, the Portacath will enable him or her to continue to swim and bathe as usual. The first couple of times that the Grippers are inserted can be stressful, but it should not hurt and your child will get used to it.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

#### **Chemotherapy and its Immediate Side Effects**

Most chemotherapy treatments for rhabdomyosarcoma involve several drugs given one after the other over a couple of days every three weeks in hospital. The first treatment may well come quite quickly after diagnosis and the insertion of the central line. Although there could be a number of side effects from the chemotherapy drugs, which can develop as you go through the treatment and are described in the next section, the major side effects felt in most cases during or immediately after the first cycle of chemotherapy, are:

#### **Nausea and Vomiting**

Your child is likely to feel sick or vomit during each stay in hospital when receiving chemotherapy and for 1-2 days after leaving hospital. Anti-sickness (anti-emetic) drugs control this side effect, but the amount and combination of drugs required differs for each child and needs some testing before being truly effective.

When your child gets home, it may take a day or so for them to recover their appetite. Offering their favourite foods can help to encourage them to eat, although you will find that their tastes may change as a result of the chemotherapy and some foods may no longer be appealing. More information about diet and getting your child to eat is contained in the next section.

### **Hair Loss**

This is the most obvious external sign of chemotherapy treatment. It usually starts a few weeks after the first chemotherapy cycle, which gives you a bit of time to prepare your child, and yourself, before it happens. Once it starts, hair loss is very quick, to the extent that it gets everywhere and can be a relief when it is all out. Eyelashes, eyebrows and other body hair will also fall out. It is often a good idea to get your child's hair cut before it starts to come out. Short hair around the house is difficult to get rid of – long hair is virtually impossible.

The most helpful thing to say to your child about his or her hair loss is that it shows that the medicine is working. In general, younger children get used to hair loss very quickly. They may wear a hat outside, but tend to pull it off whenever they are inside. Older children may be more affected by their hair loss and wigs or hairpieces, available to match your child's hair colour can be purchased. Baseball hats with fake ponytails attached can be particularly effective for girls.

All hair loss from chemotherapy treatment is temporary: the hair will return after chemotherapy is finished, but the texture and colour may change. However, if your child has also had radiotherapy treatment on his or her head, the hair in these areas may only return in patches or not at all.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

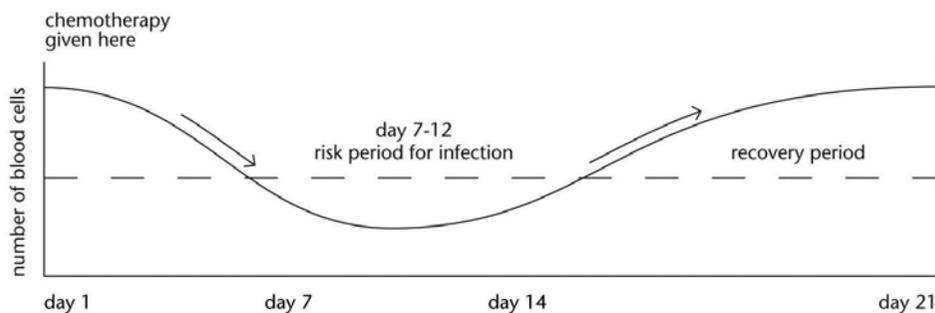
#### Effects on the Blood and the Immune System

Your blood is made up from three main types of blood cells:

- Red blood cells** – to carry oxygen around the body
- White blood cells** – to fight infections
- Platelets** – to help to clot the blood to prevent bleeding and bruising

The chemotherapy treatment reduces the number of blood cells in the body. If there are too few red cells, a person becomes anaemic, tired and pale. If there are too few white cells the person is at increased risk of infection and if there are too few platelets the person is at increased risk of bleeding. The diagram below shows the effect of the chemotherapy on the blood cells in a three week cycle:

#### The effects of Chemotherapy on blood cells



This means that from around day 7 after each cycle of chemotherapy treatment, your child is at increased risk of anaemia, neutropenia (low number of a crucial type of white cells called neutrophils), and excessive bleeding if cut or having a nosebleed.

## SECTION 2

# COPING WITH RHABDOMYOSARCOMA



Look out for high temperatures as this may be signs of infection.

Since your child will pick up infections more easily than normal when his or her blood count is low, it is important to monitor their temperature from around day 7. If your child has a temperature of 38 degrees or more this means that he or she may have an infection that needs to be treated with antibiotics in hospital. In most cases, the infection is controlled within 48 hours but longer stays may be necessary. During this time, it is possible that blood transfusions or extra platelets will be given, if these counts, too, are particularly low.

If your child has been in contact with someone who has chickenpox, shingles or measles then it is very important to let your hospital know, since your child could become ill if they catch the infection.

Over the course of treatment, each child is likely to have a number of stays in hospital between chemotherapy cycles because he or she is 'neutropenic'. At the start, you just need to be aware that this may first happen around 7-12 days after the end of the first chemotherapy cycle. If it does happen, you should pack for a few days stay in hospital. If you live relatively close to the hospital you should avoid giving your child Calpol, or any other medicine based on paracetamol, which lowers a high temperature and potentially disguises an infection that needs to be treated with different antibiotics. If you ask, the ward or outreach nurse will provide a thermometer. Alternatively you can buy one yourself – the digital-in-ear thermometers are very easy to use.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

#### **Longer Term Effects of Treatment**

You may have some concerns at the start of treatment about the longer term effects of chemotherapy and radiotherapy on your child. These are often called 'late effects'.

Current chemotherapy drugs can sometimes affect specific organs. For instance, Ifosfamide can damage the kidneys and bladder; Cyclophosphamide can affect the bladder; Actinomycin D can affect the liver; Vincristine can cause some numbness or weakness of the muscles in the hands and feet; and Doxorubicin can affect heart function. These problems are monitored carefully by nurses and doctors as treatment progresses and are often completely reversible.

Depending on the site of the tumour, radiotherapy can have some longer-term effects on your child. In particular, radiation to the brain can have important effects on body growth and development. There is also a slight risk of second tumour (benign or malignant) arising in an irradiated area but if radiotherapy is recommended by the treating team you can be sure that its benefits (in terms of the increased chance of cure of the rhabdomyosarcoma) far exceeds the risk of a second tumour. In any case, the team will be concentrating on targeting the tumour with the radiotherapy while avoiding as much of the vital organs as possible.

## SECTION 2

# COPING WITH RHABDOMYOSARCOMA

One of the main questions from parents at the outset of treatment is whether it will affect their child's fertility.

Some people think that any treatment for cancer leads to infertility. This is not true. Girls having regular periods naturally after treatment can usually become pregnant. For boys, it is more difficult to know. When your son is old enough and has gone through puberty the best way to check out his fertility is to discuss with him whether he would like to have a sperm count done. Don't be surprised if he isn't keen. Producing semen to order can be an embarrassing process and often fails in the teenage group. A blood test and a clinical examination of the testes can also be helpful in predicting future fertility in boys.

The risk to fertility depends entirely on the particular treatment that your child will receive. Chemotherapy for rhabdomyosarcoma often includes Ifosfamide or Cyclophosphamide. In high doses such as those given for rhabdomyosarcoma these two drugs have been shown to cause low sperm counts in men. The aim, however, of treatment is to avoid giving such high doses that fertility is impaired. For girls who have or are about to receive alkylating agents (Cyclophosphamide or Ifosfamide) the chances of being able to have a future pregnancy are high although there is now evidence from research that the menopause may occur earlier in life than it might have done had she not received chemotherapy. The average age of menopause in this country is around 50 years. The advice for girls would be not to leave it too late to start a family.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

Radiotherapy to the pelvis in girls or to an area that includes the testes in boys has been shown to cause a premature menopause in women and decrease sperm counts and have an effect on hormone (testosterone) in men. If your son or daughter needs to receive radiotherapy to the pelvis or lower abdomen then it is important for you to have a detailed discussion before radiotherapy treatment starts about how this might affect future fertility and sexual function. The same applies to your son or daughter if he or she is old enough to understand. Remember that many children will be concerned about this at quite a young age.

For teenage boys, there is the option of banking sperm before treatment starts. This is not an easy thing to do when you are not feeling well but it is important to try if your doctor recommends it. For girls, some centres are offering an operation to collect and freeze small biopsies from one ovary if they feel the chances of developing a very early menopause are high. This is still very experimental, but babies have been born in the world to women who have had a piece of their ovary taken and frozen before starting cancer treatment. It is something you should discuss with your doctors and nurses if you are worried.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

Most men and women treated for cancer can have normal sexual relations. The vast majority of men are able to have erections and ejaculate normally. Surgery to the pelvis is more likely to disrupt sexual function than either radiotherapy or chemotherapy. If radiotherapy has had an effect on hormone production from either the ovaries or testicles then your doctor can prescribe hormone replacement therapy.

In the longer term, and apart from some very rare types of cancer which are known to be inherited, there isn't any evidence that the children of people treated for cancer or rhabdomyosarcoma have higher risk of developing cancer than other people.

You should discuss the issue of fertility and any other longer-term effect of treatment with your consultant to ensure that you understand the impact before treatment starts.

In discussing any side effects of treatment, it is worth remembering that many of the side effects of chemotherapy, radiotherapy and surgical treatment can be managed successfully. The priority must always be to deal with the primary problem, the tumour itself.



## 'On the Treadmill'

### Hospital Stays

The protocol for your child's tumour will involve a course of chemotherapy treatment, with each cycle administered in hospital over a few days. You are also likely to be admitted to hospital for your child to receive antibiotics if they have an infection when their blood count is low. It will become routine for you to go in and out of hospital over a period of several months and there are many practical ways of helping you to manage the inevitable disruption this causes.

When your child is receiving chemotherapy, he or she is likely to feel ill for some or all of the time. It will take a few cycles of chemotherapy to refine the level of anti-sickness drugs best for your child. It is important that you know what the staff are trying each time and that you tell them what has and hasn't worked. The more experienced nurses on the ward will be most helpful in this area. They have seen lots of children's reactions to chemotherapy and will have ideas on what best to try. But do not forget that since you, the parents, are the people spending most of the time with your child you will see which combination of anti-sickness drugs is best. You should ensure that once a good combination of drugs is identified, this is the combination given each time.

It is likely that you will want to stay with your child when he or she is in hospital, not only to provide comfort and support but also to help care for him or her. Some of the chemotherapy drugs require hydration drips to be running for several hours in advance. These hydration drips are mainly sugar/salt liquid, but may also contain agents to minimise the side-effects of the drugs and help to flush them out of the body. As a result, your child will need to go to the toilet around every 2-3 hours during the hospital stay. This means that your child – and probably you – are out of bed every 3 hours each night. All urine specimens need to be tested so you will be going to the sluice with the specimen each time. You and your partner – or a close family member – may find it easier to share these nights in hospital, on a 'rota' basis, to ensure that everyone has enough sleep.

## SECTION 2

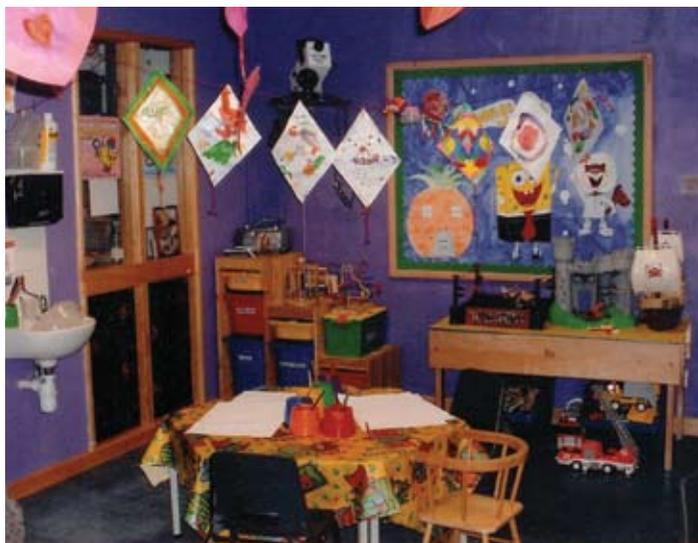
### COPING WITH RHABDOMYOSARCOMA

The nurses will advise you to use rubber gloves when you help your child go to the toilet in hospital and for the first week at home, since you should avoid contact with waste products containing even small amounts of chemotherapy drugs. This may seem odd at first, particularly at home, but quickly becomes routine.

You might be in a separate room for your hospital stays or in an open ward. In the rooms, there are additional beds for parents and in the open ward there is likely to be a camp bed that you can put up next to your child's bed.

The nurses and play specialists in the hospital will be very experienced in trying to make your child's experience in hospital as positive as possible. Oncology wards are friendly places, where the staff get to know each child well. This all helps to provide a secure and supportive place for your child.

Although there is a playroom as well as TVs and videos in hospital, you will also need to take with you into hospital lots of books and activities. It is often hard to predict how well your child might feel and having extra things to do can help pass the time for everyone.



Hospital Ward Playroom

## SECTION 2

# COPING WITH RHABDOMYOSARCOMA

Arranging for friends and relatives to come to visit will also help boost your child. You will very quickly realise the times when this is possible and the times when your child might feel too ill for boisterous company. Close friends or family can also visit your child to give you and your partner some free time to relax or eat together. Operating what amounts to a 'shift system' can be stressful and tiring for parents and help from aunts, uncles, grannies and friends to share the time in hospital is very valuable and a way to enable your wider family to help.

As treatment passes the halfway stage, the cumulative effect of the medicine may lead to a greater level of fatigue, especially if radiotherapy has been given. You will notice that your child sits out of some activities and becomes more tired in the mornings.

CLIC Sargent provide the funding for social workers who care specifically for children with cancer and their families and can help with emotional, social and practical issues in hospital and at home. For example, they can help you to apply for a 'Blue Badge' which helps hugely with parking close to the hospital (which can also be very costly), help with employment related concerns, provide information on sources of financial support and advice, be involved in your child's return to school and provide or arrange emotional support for your child or other family members.



Remember to get  
your flu jab

In the winter months, don't forget to arrange for you and your partner to get a flu jab. If you do catch flu, you not only risk passing it on to your child but it could also prevent you from going into hospital with them.

You will become used to monitoring your child's temperature between chemotherapy cycles. It is helpful to keep a regular temperature chart while you are at home and a template for this is provided overleaf. Also provided is a sheet to record your child's blood count results during the period of treatment.





## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

#### **Side-effects of Chemotherapy as Treatment Progresses**

There are several less obvious side-effects of chemotherapy which may appear from time to time, or increase over time. They will depend on the specific mix of drugs your child is receiving and range from stomach cramps and diarrhoea to mouth ulcers. The doctors will be able to prescribe a variety of medicines to alleviate these symptoms. Although they may seem individually to be minor things, they can wear down your child at a time when all of his or her defences are needed to fight the tumour. Stomach ache or mouth ulcers can be very uncomfortable for your child and anything that affects a child's appetite or causes extra absences from school should be avoided wherever possible.

Certain chemotherapy drugs can cause problems for different parts of the body, for example the liver, bladder or kidneys. If your child has had these drugs, your consultant will organise checks on these organs from time to time. Damage to these organs usually gets better with time after treatment stops.

#### **School and Activities**

A large part of normal life for school age children is attending school. Maximising the time your child is at school will help them to keep in touch with their friends in a familiar environment. Depending on their age, they may manage to keep up with their schoolwork, but this may not always be possible and is of less importance than maintaining their friendships.

It is often worrying for parents to send their child to school, particularly when they might be neutropenic or during the winter months when bugs and infections are widespread. However, in general, the benefits of being at school outweigh the risks of serious infection. Again it depends on age. If a child is at nursery school or in the early primary years, where illnesses and infections abound, attendance may be more difficult. But in later years, where most serious infections are past for most children, there is less risk.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

The school and other parents can also help. The school will send a letter to other parents asking them to alert the school nurse if their child has been in contact with someone who has measles or chicken pox, the most dangerous infections for a child with a low (suppressed) immune system. Parents of your child's classmates and particular friends can also help by keeping their own children out of school if they have a nasty flu bug or cold. Most specialists agree that the infections your child does catch are more likely to come from their inability to fight their own bugs – those that live in their noses, mouths and the gut – rather than from contact with friends and family.

The same approach can be followed with activities or clubs. If your child feels up to continuing with a particular activity and it is not too boisterous, there is no reason for them not to (other than avoiding water if they have a Hickman line). The activity or club leader will usually be happy to send out a letter to parents of the other children asking them to alert the club of any contact with serious infections.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

#### **Food and Nutrition**

Keeping your child's weight fairly stable can be a worry as he or she goes through chemotherapy. Losing a lot of weight may make them less able to withstand infection and less strong, so less able to fight their illness.

All the normal rules you have in the family about food and what your children should and should not be eating are likely to be forgotten in your efforts to get your child to eat as much high protein and high calorie foods during the times they are able to. The dietician in the hospital can help with suggestions of ways to get more calories into your child when they will eat, but the basic rule is that they should eat as much as possible of those foods normally forbidden in any diet!

You will know your child's likes and dislikes best and it is often worth giving them all their known favourites, until they object. Don't worry if they start to eat the same things again and again. There is plenty of time for them to have a balanced diet when they are eating properly after treatment has finished. Changes of taste are common during chemotherapy so be prepared for your child's tastes to change as they go through the treatment. What they love one day they might hate the next. They will also be more likely to 'graze', eating less food in one go but at more frequent intervals. Giving your child fried eggs after bedtime or several packets of crisps each day may test your resolve to the limit, but over several days, it might be the best way to keep the calorie intake up.

You may also find that you need to take food into the hospital if your child doesn't like the meals served there. Buying pizzas locally or making favourite meals at home and bringing them into the hospital helps them to eat more on a consistent basis.

If your child is losing weight despite your best efforts, the hospital will suggest some high protein, high energy supplements to be given either orally or through a naso-gastric feeding tube inserted through the nose, down the oesophagus and into the body of the stomach. This should help keep your child as strong as possible through the course

## SECTION 2

# COPING WITH RHABDOMYOSARCOMA

of his or her treatment. It is important to follow your Doctor's advice if this method of feeding is recommended. Another alternative – often very effective – is for the surgeons to insert a 'PEG' tube through the skin on the abdominal wall directly into the stomach.

### **Surgery**

Surgery is often an important part of treatment for rhabdomyosarcoma. Removing the bulk of the tumour – without causing too much damage to surrounding organs and tissues – is favoured by most consultants. The timing of the surgery will depend on the size of the tumour at the outset, how much it has shrunk through the first few cycles of chemotherapy and its location. Occasionally surgery is carried out at the time of diagnosis but will probably be recommended between the second and fifth cycle of chemotherapy.

The operation itself may be quite simple, but the results of the pathology report on the tumour removed is very important in informing you how much of the tumour has been destroyed by chemotherapy and whether there are any malignant cells remaining. The best result from surgery is that there are 'clear margins' around the tumour. This means, as far as one can tell, that the tumour has completely gone from that area. Even if some malignant cells remain, it is vital information for the oncologist and radiotherapist to know where in the operated area they are believed to be, to ensure effective targeting of radiotherapy treatment. The surgeon will 'label' the specimen so that the affected area can be identified and treated correctly.

The outcome of any surgery will probably be the last definite information you get on the progress of your child's treatment. After this, it is impossible to know whether any cancer cells remain after each radiotherapy treatment or chemotherapy cycle.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

#### Radiotherapy

Some children will need radiotherapy as part of their treatment plan and others will not. In general, radiotherapy will be needed if your child has the alveolar type of tumour and/or if, after surgery, there is microscopic evidence of malignant cells around the margin of the tumour. This is one of several reasons why the pathologist is such an important figure in the medical team.

Radiotherapy is the use of radiation treatment or high energy rays which destroy the cancer cells while doing as little harm as possible to normal cells. It is normally used to treat the local area i.e. where the primary tumour was found to maximise the chance of so-called 'local control'. There are different types of radiotherapy, some of which work better on superficial tumours sited near the skin (electrons) and others on deeper tumours (photons). A new type of radiotherapy, proton therapy, targets the tumour and delivers a smaller dose to surrounding healthy tissue. In certain situations this type of radiotherapy offers an advantage over more conventional radiotherapy. At present although the treatment is available on the NHS it means travelling to America to receive the radiotherapy as there are no proton machines in the UK. Your consultant and radiotherapist will discuss with you the reasons for the type of radiation your child will be having.

Radiotherapy is not painful and only lasts a few minutes each day. However, there is a lot of preparation to ensure that the radiographer works out the exact position in which to place your child and that treatment is given in the exact place each time. During the treatment it is important that your child remains absolutely still to ensure precise delivery of the radiotherapy.



## SECTION 2

# COPING WITH RHABDOMYOSARCOMA

Before radiotherapy actually starts, if the area to be treated is in the head or neck, a mask is made to hold the head securely in position during the radiotherapy. The mask is either made from clear plastic or from a type of mesh plastic and is attached to the table during treatment.

This is not as bad as it sounds, mainly because radiotherapy treatment only takes a few minutes. Other things can also help. The radiographers and technicians are experts at explaining each step of the process to your child, which takes away much of their fear. If your child has a favourite toy or dolly, getting a mask made for the toy can help your child get used to the process. For an older child, listening to their favourite music in the radiotherapy treatment room can help. For very young children, it might be necessary to give sedation or a general anaesthetic, to ensure that the child stays completely still during treatment. Although parents are not allowed to stay in the radiotherapy room during their child's treatment, they can watch on a CCTV screen in the next room.

Radiotherapy is given for only a few minutes every week day (not usually at weekends), but will stretch over anything from 2-6 weeks. That is up to 30 individual treatments. If possible, linking in the journey to the start or end of school can help, so that you are only making one round trip rather than several trips. For various reasons – usually because radiotherapy units are often very busy – this may not always be possible, but it's an important point to raise with the radiotherapy team, if they haven't raised it themselves.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

It is very important for your child to protect the treated area if he or she goes out in strong sunshine for at least the first year after radiotherapy.

The most common immediate side effects of treatment are sore skin around the area of treatment – like sunburn – and fatigue. The fatigue comes both from the treatment itself and from the related journeys to and from the hospital. Other side effects depend upon the part of the body being treated. For example, radiotherapy to the stomach and/or the pelvic area can cause problems such as diarrhoea, feeling sick and loss of appetite. Skin overlying the treated area is likely to remain delicate for several months so extra care should be taken.

**Communication** As you go through the treatment, you will be grateful to those people who have acted as your communicators with family, school and other groups. There will be many months where there is little to say that is new, but keeping them up-to-date with major milestones, such as surgery or radiotherapy helps them to continue to take a load off your mind.

It is important, if you can, to make sure that two of you attend the main meetings with the consultant. It is often the case that you will remember different pieces of information and you might each have different questions to ask. You should remember to bring your notes with you, so you ask all the questions you wanted to.

Even when you are midway through a course of treatment you will find that you still have to break the news to acquaintances who do not know of your child's diagnosis. Try not to be upset by their reaction. You have had several months to get used to the diagnosis but they will be shocked on hearing the news for the first time.

## SECTION 2

# COPING WITH RHABDOMYOSARCOMA

### **Siblings**

It is important as your child goes through the months of treatment that you take care that his or her siblings do not feel ignored. While they might well appreciate that you have to spend long spells of time with your child in hospital, their understanding might wear a little thin when this goes on for month after month. Their lives have changed quite a bit through their sibling's illness and they may start to feel resentful about all the attention he or she is receiving.

There are some small things you can do to help your family get through any difficult times during treatment. You and your partner spending time individually with your other children, perhaps taking them out for meals when one of you is in hospital with your ill child, can help. Making sure that when your ill child receives presents from visitors that you even things up by giving something to his or her siblings. And while all this stretching of the rules about food and discipline is going on for one child, don't forget to relax the rules for his or her siblings just a bit. Although they understand the reasons behind the changes in your behaviour, they should see some benefit too.

If your children are at school, it is very important that you keep in close touch with all their class teachers to pick up early whether there is any problem with school work or with friends at school. You might be too caught up in caring for your ill child to notice that another of your children has problems. Their teacher will be able to notice any change in behaviour and let you know.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

**Positive Thinking** During the period of treatment, you will have ups and downs. Although the first shock of diagnosis will fade and you will at least feel that action is being taken to deal with the illness, worries about your child's progress and prognosis will come back from time to time, particularly if treatment is slower than hoped or things don't go according to plan.

Although it can be difficult at times, striving to be positive about the future and about your child's recovery can help you to deal with their treatment and its inevitable side effects. Help and support from close family and friends, your church or religious group can all help to keep your spirits up. Although there is little hard data, many people believe that positive thinking can have a tangible effect on recovery from illness. At the very least, it can help to maintain the stability of your child's home environment and minimise the impact of his or her illness on the family.

It is important that you maintain many of your usual social activities, to keep your own lives as normal as possible and to give you a break from the worry and stress you will inevitably feel as your child goes through their treatment.

It can be a good idea to have short term targets for the whole family to enjoy, perhaps when you begin to work out your child's best days within the chemotherapy cycle i.e. plan a trip to the cinema, enjoy the company of another family over pizza. It's good for everyone to be distracted for a couple of hours at least!

**Complementary  
(Alternative)  
Therapy**

Surveys of families affected by cancer indicate that up to 80% use some sort of complementary therapy during or after the 'medical' treatment has been given. In the past, alternative or complementary medicine was dismissed by many doctors but it is recognised now that families often benefit from the positive effects of treatments such as acupuncture, massage, counselling or nutritional therapy.

Several effective cancer drugs are derived from natural sources, especially fungi and plants. The main 'problem' with complementary therapy is that individual treatments are hardly ever subjected to the same intense scrutiny and 'clinical trials' as official drugs, and that is a matter of considerable concern. It is therefore important that you discuss with your consultant any of the alternative therapies you plan to use, to ensure that they do not interact in any harmful way with your child's medication. Herbal 'remedies' are a case in point since some of them are known to interfere with medically-prescribed drugs proven to help children with cancer. The following are just some of the over-the-counter treatments that interfere with the action of cancer drugs or other medicines, such as antibiotics – bilberry, echinacea, fish oils, garlic, glucosamines, meadowsweet, selenium and St John's wort.

## End of Treatment

However much your lives were disrupted by your child's illness and however long you knew the precise date the treatment would end, leaving hospital after the last chemotherapy cycle or neutropenic episode still comes as something of a shock.

Even though treatment may have been difficult, it provided the assurance of being in contact with the hospital and taking action to treat the illness. Many parents say that they had the feeling that the disease had only been held at bay while the drugs were being given. It is not uncommon to think that stopping treatment is tempting providence, that the 'safety net' has been removed.

When the course of treatment is over, you may well experience a heightened fear of the return of symptoms. The initial anxiety about your child's condition might also return at this time. You might be surprised at how fed up you feel. This renewed uncertainty can be eased a little by the regular follow ups that your child receives. Your consultant and the medical team know that this is a common reaction and someone will always be there at the end of the telephone, between clinic visits, to deal with your concerns and worries. Don't spend days worrying at home about anything – do seek help.

If your child has a relapse and the tumour returns, other treatments will be planned by your child's consultant and discussed with you in detail. Since the drugs will usually differ from those already given, you need to ask about their side-effects and late-effects too.

## SECTION 2

### COPING WITH RHABDOMYOSARCOMA

The current average cure rate for rhabdomyosarcoma is between 60-70% overall, with slow but steady further improvements happening all the time, at a rate of approximately 1-2% per year. The greatest risk of relapse is during the first year off treatment, with a lesser risk each succeeding year for up to 5 years after the end of treatment. If your child reaches 3 years off treatment and is still in remission, the chance of cure is >95%.

It can take a few months for your child to regain full strength again and you should be guided by them as to what they feel able to do when. It is important that all family members – and especially siblings – are treated equally as life gradually gets back to normal. Do remember the distress of the past few months takes some time to fade, for children and parents alike.

It is really only time and regular clear checks that will give you the confidence that your child's symptoms will not recur and the cancer is completely cured. As the months pass, you will begin to feel a little less fraught and able to enjoy your child's good health more and more each day.

Your medical team is very aware that this is an uncertain and worrying time for families. They are only a phone call or a clinic visit away and can provide help and support as often as it is needed during the months and years after the end of treatment.



## **SECTION 3**

### REFERENCE

The Medical Team

Glossary of Terms

Helpful Website References

# 3

## **The Medical Team**

You will meet lots of different people in hospital and it is worth understanding the role of each person so that you can direct your questions to the right person.

### **Consultant Paediatric Oncologist**

The senior doctor who will be responsible for all the major decisions which need to be taken about your child and his or her treatment. This is the person with whom you should discuss important issues about your child's condition and treatment plan.

### **Associate Specialist**

Senior doctor who works in the ward or clinic on a permanent basis.

### **Registrars and Senior House Officers**

These doctors will be involved in the day to day care of your child when he or she is in hospital. Most of the tests and treatment are done by these doctors under the supervision of the consultants. These doctors may still be training and move from one ward to another, so you may meet several of them during the course of your child's treatment.

### **The Nurses**

The nurses are there to take care of your child in hospital, will administer all the drugs they need and advise you on how to care for your child at home after hospital visits. The sister or charge nurse is in charge of the ward and staff nurses and student nurses work under their direction. All the nurses on the oncology ward have had special training and the handling and administration of chemotherapy is their particular responsibility. They are also skilled at dealing with the side effects, especially anti-sickness drugs.

#### **Surgeons**

Surgeons may take a biopsy, remove a tumour, put in central lines or 'PEGS'. The consultant surgeon liaises very closely with the consultant oncologist in your child's overall treatment plan, particularly on the timing of surgery.

#### **Outreach Nurses**

Outreach nurses support you as you care for your child at home, particularly if you live quite a distance from the hospital. The outreach nurses will visit your GP and your child's school with you to explain your child's condition and treatment to the teaching staff and may also arrange to meet with your local community nurse.

#### **Pharmacists**

The pharmacist is responsible for preparing and dispensing the drugs your child receives and providing advice on all drug issues.

#### **Play Therapists**

Play therapists are trained to help children cope with the experience of being ill and in hospital by using play. There will often be a playroom on the ward, which helps children to forget their fears through painting, drawing and playing. Children can also be provided with play therapy in their cubicle or bed if they are unable to go to the playroom.

#### **Psychologist**

A psychologist may be able to help children who have difficulties with behaviour or learning during their treatment. They can also help the whole family to deal with the stress of the illness and treatment.

#### **Hospital School Teachers**

During your child's time in hospital, it is important that he or she does not fall too far behind with school work. The hospital school teacher will visit the ward to work with your child on a one-to-one basis to catch up on the school work he or she may be missing. If your child is at home and off school, the hospital teacher may be able to visit you at home.

## SECTION 3

### REFERENCE

#### **Dietician**

Dieticians look after the nutritional needs of your child during treatment. If you are worried about your child losing weight, then a discussion with the dietician may give you ideas on different foods to try with your child. They can also advise on other forms of nutrition, such as high energy supplements, through a naso-gastric feeding tube or a 'PEG' (see glossary).

#### **Social Workers**

Social workers help with practical and financial problems families may face. These range from helping to obtain the non means-tested disability allowance and disabled persons parking badge to recommending the best providers of travel insurance for people with medical conditions. CLIC Sargent provides the funding for social workers who care specifically for children with cancer and their families.

#### **Dentists**

There will usually be dentists based in the hospital who will check your child's teeth while he or she is receiving treatment. The dentist will take particular care to check your child's teeth before embarking on chemotherapy or radiotherapy treatment to the head or neck, to ensure that there is little or no decay. Both radiotherapy and chemotherapy can aggravate the effect of decay on teeth.

#### **Consultant Radiotherapist (sometimes known as Consultant Clinical Oncologist)**

Radiotherapists are doctors who specialise in radiation treatment. Your child's radiotherapy treatment will be planned by the consultant and given by a team of radiographers.

#### **Your own GP**

Throughout your treatment, you will have little formal contact with your own GP as any queries about your child's treatment should normally be directed to your main treatment centre. However, the discharge notes provided by the hospital after each stay will keep your GP up-to-date with your child's treatment in case you do need to seek help from him or her.

## **Glossary of Terms**

<b>ALLERGY</b>	An extreme sensitivity to a substance which may have to be avoided thereafter.
<b>ALOPECIA</b>	Hair loss.
<b>ANAEMIA</b>	The condition of having less than the normal amount of haemoglobin.
<b>ANALGESIC</b>	A drug used for reducing pain.
<b>ANTIBIOTICS</b>	Drugs which destroy or stop the growth of bacteria and help to stop infection.
<b>ANTIEMETIC</b>	A medicine which controls nausea and vomiting.
<b>ANTIFUNGAL</b>	A medicine that kills fungi, organisms to which children with cancer are especially vulnerable.
<b>BENIGN</b>	Can be a tumour but does not have the ability to spread to other sites.
<b>BIOPSY</b>	A small piece of tissue taken from any part of the body in order to examine it under a microscope to make a diagnosis.
<b>BLOOD TRANSFUSION</b>	Introducing whole new blood or components into the patients circulation.
<b>BONE MARROW</b>	A spongy material in the centre of the large bones. Produces all the different blood cells.
<b>CANCER</b>	Abnormal growth of cells (primary tumour) in the body which may spread to other sites and create secondary tumours.
<b>CATHETER</b>	A thin flexible tube used to pass fluid into the body or to drain fluid from the body (for example a central venous catheter – central line – or a urinary catheter).
<b>CELL</b>	The living units from which animals and plants are built i.e. blood cells, brain cells. They are so tiny that 1,000,000 cells would sit on the head of an ordinary pin.
<b>CENTRAL LINE</b>	A tube inserted under the skin into a large vein to make the giving of drugs and the taking of blood samples easier.

## SECTION 3

### REFERENCE

<b>CHEMOTHERAPY</b>	Drug treatment to kill cancerous cells.
<b>CHROMOSOME</b>	Structures in the cell core (nucleus), containing the genes.
<b>COMPUTERISED TOMOGRAPHY</b>	CT Scan – makes a cross-sectional x-ray picture of a 'slice' of the body.
<b>CONGENITAL</b>	Any condition existing at birth.
<b>CULTURE</b>	When infection is suspected, samples of blood, urine, throat secretions etc are taken to identify the organisms that are present and the most effective antibiotic to eradicate them.
<b>DIAGNOSIS</b>	The exact name and type of the patient's illness.
<b>ELECTROLYTES</b>	A general term for the many minerals necessary to provide the proper environment for the cells of the body. Include calcium, potassium, sodium, chloride and bicarbonate.
<b>EMESIS</b>	Vomiting.
<b>ENTERAL FEEDING</b>	Feeding through a tube directly into the stomach. There are 2 methods: (1) a tube is passed down through the nose (an 'NG' – nasogastric – tube) or (2) a connection is made between the stomach and the skin of the abdomen via a short operation ('PEG' tube). Both kinds of tube can safely stay in place for months.
<b>FEBRILE NEUTROPENIA</b>	Having a fever (raised body temperature) because of lower immunity to infection when there are less than the normal number of neutrophils in the circulating blood.
<b>GASTRO INTESTINAL</b>	Relating to the stomach and the intestines.
<b>GLOMERULAR FILTRATION RATE</b>	GFR – A test to see how well the kidneys are working.
<b>HAEMATOLOGY</b>	The study of blood and blood diseases.
<b>HAEMATURIA</b>	Blood in the urine.
<b>HAEMOGLOBIN</b>	The substance within red blood cells which carries oxygen to the tissues of the body.

<b>HAEMORRHAGE</b>	Bleeding.
<b>HISTOPATHOLOGY (PATHOLOGY)</b>	The microscopic study of cells in disease processes.
<b>HYDRATION</b>	Defines the status of the patient with regard to body water: he may be dehydrated (too little), well hydrated (normal) or excessively hydrated (too much).
<b>HYPOTENSION</b>	Low blood pressure.
<b>ILEUS</b>	A condition, usually temporary, when the bowel stops functioning properly. It is commonest after abdominal surgery.
<b>IMMUNE SYSTEM</b>	The body's defence against infection, disease and foreign substances.
<b>IMMUNO-GLOBULIN</b> i.e. <b>HIG, ZIG</b>	A substance containing antibodies. It is sometimes injected into children who have been exposed to measles or other infections in order to help make the course of the disease milder.
<b>IMMUNO-SUPPRESSION</b>	Suppression of the immune system leading to an increased susceptibility to infection.
<b>INFUSION</b>	The introduction of a fluid into a vein.
<b>INTRAVENOUS (I.V.)</b>	The administration of a drug or fluid directly into a vein.
<b>IVAC, IMED PUMPS</b>	Machines that regulate the flow of IV fluids automatically.
<b>KIDNEY</b>	The chief organ involved in excretion of soluble bodily wastes and in the maintenance of proper mineral and water balance.
<b>LAPAROTOMY</b>	Any surgical procedure that involves entering the abdominal cavity.
<b>LESION</b>	A change in tissue structure due to injury or disease. Ulcers, tumours abscesses etc may all be referred to as lesions.
<b>LEUCOPENIA</b>	A lower than normal total number of white blood cells in the circulating blood.

## SECTION 3

### REFERENCE

<b>LEUCOCYTOSIS</b>	A higher than normal total number of white blood cells in the circulating blood.
<b>LIVER</b>	The organ that performs many complex functions necessary for life, including processes related to digestion, production of certain blood proteins and elimination of many of the body's waste products.
<b>LOCAL CONTROL</b>	The complete and permanent eradication of the tumour from the primary local site. The primary site is usually the most difficult cancer site to treat effectively.
<b>LYMPH NODES</b>	Part of the body important in defence against infections, commonly known as 'glands'.
<b>LYMPHOCYTES</b>	White blood cells responsible for the production of antibodies and for the direct destruction of invading organisms.
<b>MALIGNANT</b>	Cancerous, potentially spreading to certain other parts of the body. The opposite of benign.
<b>METASTASIS</b>	The spread of cancer from its original site. Also known as secondary tumour.
<b>MUCOSITIS</b>	Inflammation of the mucous membrane, e.g. inside the mouth.
<b>NAUSEA</b>	Feeling sick!
<b>NEOPLASM</b>	Another word for tumour – can be benign or malignant.
<b>NEUROLOGY</b>	Branch of medical science dealing with the nervous system.
<b>NEUTROPHILS</b>	White blood cells which fight acute infection.
<b>ONCOLOGY</b>	The study, diagnosis and treatment of tumours, especially cancers.
<b>PAEDIATRIC ONCOLOGY</b>	The branch of medicine which specialises in the study and treatment of child cancer.
<b>PALLIATION</b>	Relief of a symptom (like pain) but not necessarily a cure.
<b>PANCYTOPENIA</b>	Decrease of red cells, white cells and platelets in the blood.

<b>PARENTERAL FEEDING</b>	A method of delivering nutrition or other substances directly into a vein (IV).
<b>PEG</b>	Percutaneous Endoscopic Gastrostomy. A tube is inserted into the stomach through the abdominal wall to provide nutrition for a period of several months.
<b>PET SCAN</b>	Positron Emission Tomography Scan. Sometimes used for diagnosis, but not an essential part of the diagnostic process.
<b>PLASMA</b>	The liquid portion of blood. It's a colourless fluid which contains water and other components in which red cells, white cells and platelets are suspended.
<b>PLATELETS</b>	The tiny cells in circulating blood which aid blood clotting.
<b>PRIMARY TUMOUR</b>	The tissue or organ in the body where the tumour originally started growing.
<b>PROGNOSIS</b>	An estimate of the outcome of a disease based on the patient's current condition and accumulated medical knowledge about that disease and its best treatment.
<b>PYREXIA</b>	Fever/abnormally high body temperature.
<b>RADIOTHERAPY</b>	Treatment with x-rays, or radium cobalt and other radioactive substances.
<b>RED BLOOD CELL</b>	The oxygen carrying cell in the blood which contains the pigment haemoglobin. Produced in the bone marrow.
<b>REFRACTORY TUMOUR</b>	When the cancer is resistant to treatment.
<b>REGIONAL SPREAD</b>	A tumour that has extended beyond the limits of the organ where it started, growing directly into immediately surrounding organs or tissues, but has not spread to distant parts of the body.
<b>REGRESSION</b>	Shrinkage of a tumour/cancer as a result of therapy.
<b>RELAPSE</b>	The reappearance of cancer following a period of remission or absence of 'active' disease.
<b>REMISSION</b>	A period of well-being with no signs of disease. There is no longer any evidence of the disease using the available investigations.

## SECTION 3

### REFERENCE

<b>RENAL</b>	Relating to kidneys.
<b>RESPIRATION</b>	The process of breathing.
<b>SARCOMA</b>	A cancer of connective tissue, bone, cartilage, fat, muscle, nerve sheath or blood vessels.
<b>SECONDARY TUMOUR</b>	Metastasis – spread of malignant tumour from its original site through the bloodstream to one or more other tissues.
<b>SEPSIS</b>	Any form of infection.
<b>SEPTICAEMIA</b>	Bacterial growth within the bloodstream.
<b>SHINGLES</b>	Herpes Zoster. A virus infection of the skin by the same virus that causes chickenpox.
<b>SINUSES</b>	Hollow spaces in bones of face.
<b>SPLEEN</b>	An organ near the stomach. It's composed mainly of lymphocytes and is part of the immune system.
<b>STAGING</b>	'Staging' describes the extent to which a tumour has spread at diagnosis as judged by scans and other tests.
<b>STEM CELLS</b>	A 'parent' cell whose division results in the development of more specialised cells.
<b>STOMATITIS</b>	Mouth sores.
<b>TEMPERATURE SPIKE</b>	When the body temperature suddenly goes up.
<b>THROMBOCYTOPENIA</b>	Less than the normal number of platelets in the blood.
<b>TOXICITY</b>	Property of producing unpleasant or dangerous side effects of treatment.
<b>URINARY TRACT</b>	The organs that have to do with the production and elimination of urine, i.e. kidneys, ureters, bladder, urethra.
<b>VARICELLA</b>	Chickenpox, an infection caused by the Varicella Zoster virus (VZV). The same virus causes shingles.
<b>VIRUSES</b>	A group of very small organisms which can produce disease. Common viral infections include: measles, mumps, chickenpox and the common cold.

## SECTION 3 REFERENCE

### **WHITE BLOOD CELLS**

Cells in the blood that are most important in fighting infection, e.g. neutrophils, lymphocytes, etc.

### **ZOSTER IMMUNE GLOBULIN (Z.I.G)**

A special plasma containing antibodies against chickenpox. It seems to be effective in reducing the severity of the chickenpox after exposure. It is given by needle directly into the muscle.

## Helpful References

### General Information

- CLIC Sargent**      [www.clicsargent.org.uk](http://www.clicsargent.org.uk)  
CLIC Sargent offers individual support to families affected by cancer through clinical, psychosocial, emotional and financial services in hospital, at home and in the community across the UK.
- Teenage Cancer Trust**      [www.teenagecancertrust.org](http://www.teenagecancertrust.org)  
The Teenage Cancer Trust funds and builds specialist units for young people in NHS hospitals, provides a family support network, funds research and educates young people in the UK about cancer, prevention and healthy living.
- Cancer Research UK**      [www.cancerresearchuk.org](http://www.cancerresearchuk.org)  
Leading UK charity for all adult and children cancer types, Cancer Research UK is the biggest single independent funder of cancer research in Europe.

### Benefits Advice

- CLIC Sargent**      0300 330 0803
- Macmillan**      [www.macmillan.org.uk/howwecanhelp/financialsupport/benefitsadvisers/Macmillanlocalbenefitsadvisers.aspx](http://www.macmillan.org.uk/howwecanhelp/financialsupport/benefitsadvisers/Macmillanlocalbenefitsadvisers.aspx)



Claire aged 14 years, between her friends Catriona and Erika.

[www.rhabdomyosarcomabooklet.org.uk](http://www.rhabdomyosarcomabooklet.org.uk)