

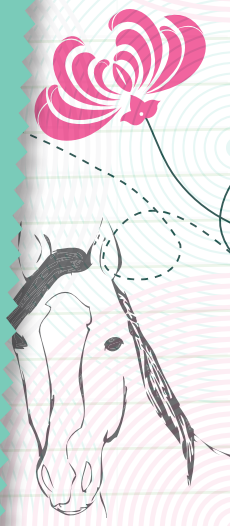
Diffuse Intrinsic Pontine Glioma

Questions, answers & thoughts

Written on behalf of The Katie McKerracher Trust

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Introduction

This booklet was written on behalf of the Katie McKerracher Trust which was set up in memory of our daughter Katie who was diagnosed with a Diffuse Intrinsic Pontine Glioma (DIPG), a tumour in her brain stem, in February 2008.

When Katie was diagnosed, aged just 10, our family was thrown into emotional turmoil and we were in desperate need of information on the disease and support to help us through this traumatic experience. We received great support from the medical team but found there to be a lack of relevant information available to parents on this rare disease and so decided to produce our own booklet. This has been possible thanks to guidance from the Royal Hospital for Sick Children in Edinburgh, and professional advice has been provided by Dr Mark Brougham and Dr Simon Bailey who who were both involved with Katie's treatment.



Over a period of five to six weeks Katie had progressively begun to suffer dizziness, nausea, and an increasing lack of confidence. After several visits to the doctors she was referred to the Borders General Hospital in Melrose for an MRI scan and we were told the devastating news that she was suffering from a terminal illness and had from six to 12 months to live. After a six week radiotherapy and chemotherapy treatment programme Katie was in a wheelchair and unable to walk. At the end of May 2008, having had an operation to remove fluid from her brain, doctors told us they could offer no further treatment as Katie's blood counts had suffered so badly from the chemotherapy treatment. By the end of June 2008 Katie could not walk, talk or eat.

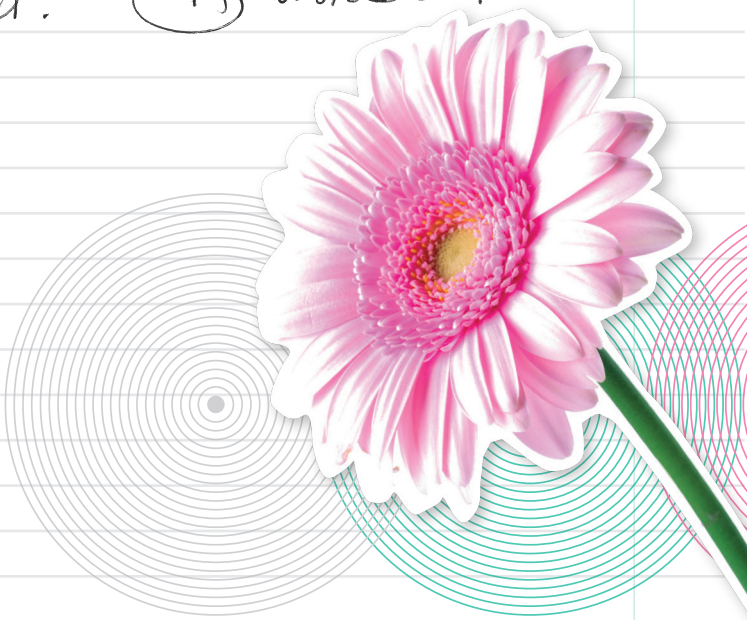
We began to see a healer and Katie showed remarkable improvement – whether this was down to the medical treatment or the healer we will never know but it meant that Katie was soon able to chat, draw, and give her two brothers cheek again.

There was a huge improvement in Katie's health for a three month period but sadly she began to deteriorate once more and passed away four months later, in January 2009, having suffered respiratory failure. Life for our family has a huge hole which we can never fill and it made us determined to help patients and family members going through the same experience.

This booklet explains the various stages you are likely to go through, from the shock of diagnosis and embarking on a treatment plan to the importance of keeping a diary, maintaining regular and effective communication, asking questions, and how to cope with the effects of the disease as a family on a day-to-day basis.

We have also included information on the medical team members you're likely to come into contact with, plus a section on the Katie McKerracher Trust and how it can - and does - help families like yours.

We hope you find this booklet useful and informative. Please contact us directly on **Tel: +44 (0)1750 52387 / email: info@katiemckerrachertrust.co.uk** for further support should you need it.



Foreword

by Dr Simon Bailey

I would like to offer my thanks and support for the work and effort that has gone into making this instructive booklet which I am sure will be invaluable to the young people and their families who have to deal with such devastating news.

Katie was a very brave young lady and her courage and that of Ann and Andrew in dealing with this illness is an inspiration to others. The practical advice offered in the booklet will be very useful as it is written by two people who have travelled this difficult journey themselves. It is reassuring to other parents and family members, as well as the children and young people themselves, that there is non-medical peer support available from people who truly understand.

DIPG is unfortunately a devastating condition and until now we have made very little progress with being able to give effective treatment. However there is hope on the horizon. A major effort is being made to understand the biology of this disease and, in the last two years, the first biological studies have been published. Further studies are expected and, armed with this important information, drugs and novel treatment will be targeted against the tumour cells. It will take a while to see the potential benefits but at least the war against DIPG can begin in earnest.

You may be asked various questions about participating in studies or about permission to take a biopsy. You may be bombarded with information at what is a challenging time and asked to make decisions which seem very difficult. It is important to remember that there is no wrong answer for you or your child/young person and these decisions are wholly dependent on individual circumstances. The health professionals will support you whichever decisions you make and you will be supported equally regardless of the direction you choose to take.

Most importantly I would like to salute the children and young people like Katie who deal with this tumour. We all have a lot to learn from them and it is a privilege and an honour to be able to help them. We hope to offer more to these young people in the future.

Dr Simon Bailey
Consultant Paediatric Oncologist

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Section 1

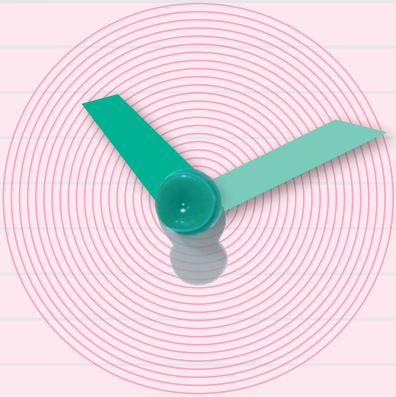
Initial Impact

If you have recently been told that your child is suffering from a DIPG you will be feeling shocked, bewildered, and frightened about the future. You may not know much about cancer as a group of diseases and are trying to link what you do know to your child's condition.

We were told that Katie may live for six, nine or 12 months, which of course was incredibly hard to take in and we were thrown into a fast-moving, unknown world which we were desperate to escape from. It is very important that you rely at this time on the information given to you by your consultant and his or her team. Try not to be overly distracted by what other, no doubt well-meaning, people may tell you and always feel that you can plan for your child as well as question what is happening.

You will receive so much information at the time of diagnosis that it's impossible to take it all in so this booklet aims to enable you to take one step at a time by covering most of the issues which may occur at different times throughout your child's treatment.

Cancer is a word which covers a huge range of conditions which differ in cause, treatment and cure so it's vital you focus on your own child and the facts of his or her particular situation. And be sure to think about the options available before deciding the best way forward for your child.

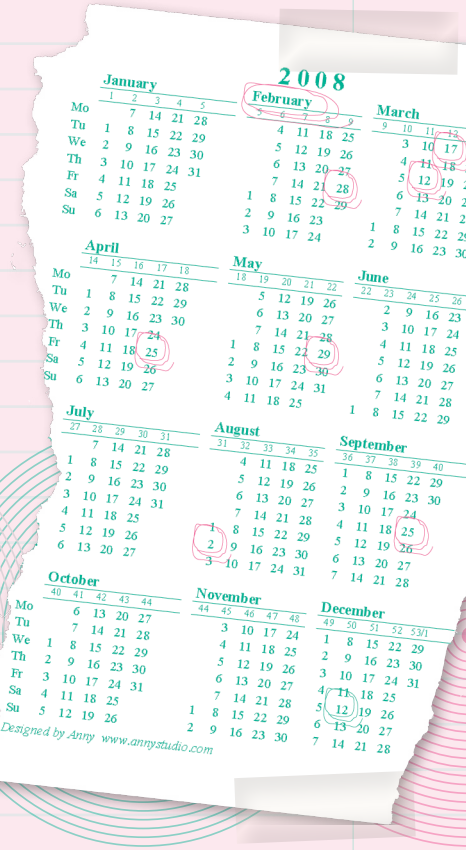


Keeping a Diary

Diagnosis and treatment of a DIPG is something which the whole family, not just your child, goes through. There are many practical things you and your family can do to help everyone cope with what could be many months of treatment and time spent in hospital.

Keeping a diary from day one is a good way to keep track of your child's progress as well as being a useful tool enabling you to look back on how the treatment programme developed over time. You may wish to keep a record of your child's blood counts as this can be useful for the medical team.

There are pages included at the back of the booklet for you to make notes and 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 team(s). Having a ready list of questions – and writing down their answers at the time – can help act as a reminder for what you really want to ask and need to remember about your child's treatment. As you get into a routine you will find that some queries can be dealt with on the spot while others may need a setting and time when unhurried discussion can take place. Don't be afraid to ask for a specific meeting to accommodate this.



If a medical person has said something you don't understand or agree with, ask to have it clarified or to discuss the options further. You need to feel that the right things are being done for your child and family.

Section 1

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 known as a tumour.

Cancer in children is rare and thankfully numbers of cases are not increasing but there are still 1200 new cases each year in the British Isles.

What is Diffuse Intrinsic Pontine Glioma?

A DIPG is a tumour in the brain stem. These tumours - which are malignant and grow rapidly - are inoperable because they are located in such a critical part of the brain, and the mass of the tumour is a combination of both good and bad cells.

The average age of patients is between five and ten years old and around 35 children are diagnosed in the UK each year. Most children die within 12 months of diagnosis.

In Katie's case we noticed lots of small changes over a period of five weeks. She felt faint and bumped her head getting out of the shower, which we put down to tiredness (Katie was a very keen dancer). Looking back this was the first sign that something was wrong. She then started to feel unbalanced when walking which, in hindsight, got progressively worse. Katie also started vomiting in the mornings, and generally lost her confidence.

Symptoms are varied depending on the child and can include:

- Muscle weakness on one side of the body
- Problems with swallowing
- Speech problems
- Crossed eyes/squinting
- Drowsiness
- Headaches (can be worse in the morning but not necessarily)

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Section 2

Diagnosis and Treatment

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

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

People deal with bad news in different ways and over the first few days it is important to give your spouse, partner and family members space to get used to the news in their own way.

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, once you've decided to go ahead with treatment it is important to start it promptly.

It may help you at this stage to hear about Katie's experience as it illustrates the various stages you are likely to go through with your child.

Katie's symptoms appeared gradually and we had been to our GP on several occasions; firstly we were told to come back if we were still concerned and then, at an out-of-hours surgery, she was diagnosed with Labyrinthitis (an imbalance in the inner ear which causes severe dizziness) and given medication for it. After a week of taking this medication we went back to our local GP and, after some simple tests (such as walking a straight line and pointing to the GP's finger), a referral was made to our local hospital. Katie was seen the next day by a consultant and eye specialist who both found nothing wrong but said they would carry out an MRI scan as the only place they couldn't see was the back of Katie's head.

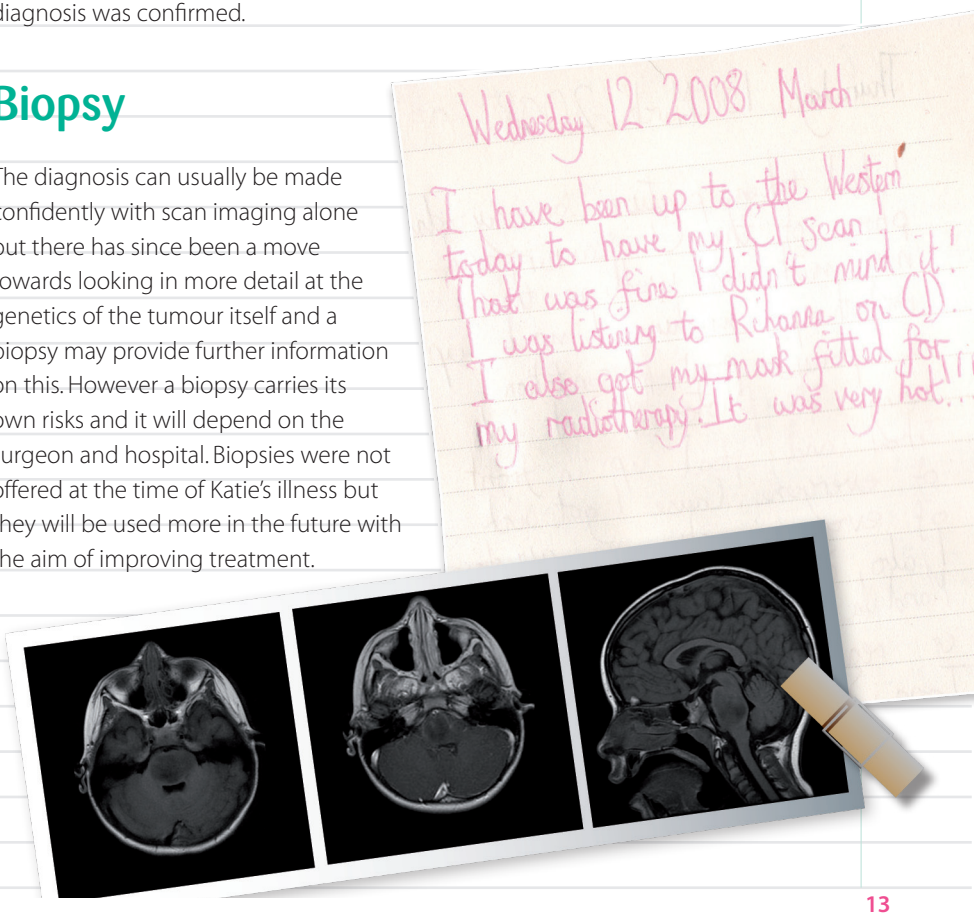
MRI and CT Scans

An MRI scan is very useful as it provides a detailed picture of what is going on inside the brain. A CT scan does not give as much detail as an MRI scan but can give information on whether fluid is draining properly from the brain, is quicker to carry out, and can be less frightening for children. MRI scans take much longer to carry out (it can be around half an hour) and general anaesthetic may be needed (usually for children under the age of five) as the child must be completely still throughout the procedure.

When the MRI scan was carried out on Katie, they informed us they had found a tumour and we were kept in Borders General Hospital overnight and taken by ambulance the next day to Edinburgh's Royal Hospital for Sick Children, where the diagnosis was confirmed.

Biopsy

The diagnosis can usually be made confidently with scan imaging alone but there has since been a move towards looking in more detail at the genetics of the tumour itself and a biopsy may provide further information on this. However a biopsy carries its own risks and it will depend on the surgeon and hospital. Biopsies were not offered at the time of Katie's illness but they will be used more in the future with the aim of improving treatment.



Section 2

Steroids

Katie was immediately started on steroids which are used to reduce swelling around the tumour and the brain. Steroids are likely to be administered at the diagnosis stage and they will also be required at later stages during treatment. This is ideally given as 'pulses', with a short course of a few days and then weaned off, as this gives maximum benefit and fewer side effects. However, some children may require steroids for a much longer duration during treatment. Dexamethasone is the main steroid used.

Side effects:

- Irritation of the stomach lining - Omeprazole or Ranitidine is given to help with this
- Swollen tummy and chubby cheeks
- Increased appetite – your child may put on weight quickly but he or she could appear to be thin elsewhere. Although Katie's appetite was ravenous and she put on weight all over, this will depend on the child. The often speedy change in a child's appearance can be very upsetting for parents so do bear this in mind
- Steroids can affect mood so the child may become hyperactive or upset and emotional, or fluctuate between the two
- They can disrupt sleep patterns so tend to be given in the morning and at around 2pm to avoid this

The Treatment Plan

Your consultant will explain the treatment plan (sometimes referred to as the protocol). This is a plan for the best combination of radiotherapy, chemotherapy and any other treatment needed for your child.

The protocol shows the frequency and length of radiotherapy and chemotherapy, as well as telling you how long the whole treatment plan is expected to take (usually between five and 12 months). There is likely to be a major assessment of progress including repeat scans with your consultant every two to three months or at significant points. Depending on this the treatment plan may change accordingly.

Portacath and Hickman Lines

Central lines are for venous access (access through the vein) to give intravenous medicines and take blood samples. Over the next few weeks preparations were made for Katie to start radiotherapy and chemotherapy which involved her having a portacath, or 'port' fitted. 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. It can be distressing for the child having the port fitted but most children will take this in their stride. Some children will not be offered a portacath; this will depend on the hospital. When not in use the port lies completely under the skin, with no external parts. When the port is used a 'Gripper' needle is placed into the port, which is usually well tolerated by the child.

A Hickman Line is an alternative to a port, and involves the tubing lying permanently out of the skin. It can be useful for younger children or those who will not be able to tolerate the Gripper needle being inserted. However, this is more restrictive, particularly with activities such as swimming.

Some children, particularly those who are older, may not require a central line at all.

Nasogastric Tube or PEG

A nasogastric tube or PEG may need to be fitted to help feed your child. The nasogastric tube goes in through the nose and is used to administer food and medicine. It can be upsetting for the child and parents putting this in but once it is in most children are not too bothered by it. Andrew learned how to put Katie's tube in – he found it daunting at first but once he had the hang of it there were no problems.

The PEG goes in through the stomach and an operation is required. Unlike the nasogastric tube, you can't see it but it can become infected.

It's important to consider both options, and ask questions if you're not sure of anything to make sure you're making as informed a choice as possible.

Section 2

Radiotherapy

Radiotherapy is the use of radiation treatment (high energy rays like x-rays) which destroys cancer cells while doing as little harm as possible to normal cells.

A mask is made, by taking a mould of the child's face shape, which then has to be worn for around half an hour while the child remains very still. A simulation session, which lasts around 20 minutes, will be carried out where the child lies down wearing the mask while measurements are checked to ensure the treatment is targeting the right place.

Radiotherapy involves treatment of the area for six weeks, Monday to Friday. The preparation is very important and younger children (under five to six years old) will possibly need a general anaesthetic every day of their treatment as they need to stay very still so that the treatment is targeting the exact location. Bloods should also be checked weekly during radiotherapy.

Parents should remember that play specialists, if available, have an important role in preparing children for treatment and their input may mean a general anaesthetic is not required.

The treatment lasts only a few minutes but parents may need to organise to be resident in the city where treatment is taking place in order to avoid long journeys each day. Your CLIC Sargent or outreach nurse, based at main treatment centres, will be able to help you with these arrangements.

Side effects:

- Hair loss (this tends to be on either side of the head)
- Nausea/vomiting
- Painful throat
- Tender skin
- Affects appetite – it is likely your child's appetite and palate will change dramatically


Katies Mask

A scan will be carried out four to six weeks after radiotherapy (to allow time for any swelling to go down) to see if there has been any change to the tumour. Sometimes the scan is difficult to interpret as the tumour may look worse even at this stage due to swelling. The aim of this treatment is to slow progression of and shrink the tumour as well as to aid quality of life, rather than cure the disease. The effects of radiotherapy do go on beyond when the treatment has ended (for up to three months).

Chemotherapy

Chemotherapy is the use of drugs to destroy cancer cells. Many different chemotherapy drugs have been used to treat DIPG, but sadly none have been shown to cure this tumour. However, like radiotherapy, chemotherapy can be used to slow down growth of the tumour and prolong quality of life. The chemotherapy agent currently used for this purpose is Temozolomide, which is started during or after recovery from radiotherapy. Temozolomide, which is taken orally in liquid or capsule form, can be given once a day, for three weeks on and one week off, or for five days in every four weeks at a slightly higher dose. The child is reviewed regularly and another scan performed a couple of months later.

Side effects:

- Hair loss
- Nausea and vomiting – your child can feel sick or vomit when recovering from chemotherapy; anti-sickness medicine is therefore given to prevent this, but if nausea or vomiting still occurs other anti-sickness medicines can be used
- Treatment can affect blood counts so the child may need blood or platelet transfusions
- Infections are more likely – if your child develops signs of an infection they must be seen in hospital promptly, and will almost certainly require antibiotics
- Pneumonia – Pneumocystis, a bug that usually lives harmlessly in the nose, can develop into a particular type of pneumonia when on chemotherapy treatment. The drug Cotrimoxazole would be administered three times a week to try to prevent this
- Affects appetite – it is likely your child's appetite and palate will change dramatically

Blood Tests

Children are reviewed continually on a weekly basis to check blood counts and keep their haemoglobin levels up, and we attended the Royal Hospital for Sick Children in Edinburgh once a week for Katie's blood tests.

The chemotherapy treatment reduces the number of blood cells in the body and if there are too few red blood cells a patient becomes anaemic, tired and pale. If there are too few white blood cells, which fight infection, the patient is at increased risk of infection. Since your child will pick up infections more easily than normal when their blood count is low, it's important to be vigilant and regularly check body temperature – 38 degrees or more and they may have an infection which will need to be treated with antibiotics. If you are concerned about your child at any stage during treatment, even if their temperature is not high, you must contact the hospital team.

After four weeks of treatment Katie's blood count was struggling and after five weeks her platelet count was very low. This can cause excessive bleeding so she had to receive a transfusion. The chemotherapy treatment was stopped at this point but Katie continued radiotherapy for the full six weeks.

Remember that you should not feel pressured into your child receiving any form of treatment as this decision is entirely up to the family. Make sure you understand the implications of all the possible options so that you're making as informed a choice as possible.

Clinical Trials

Patients diagnosed with cancer may be eligible to take part in a clinical trial. If there is a trial open for children with DIPG (at the time of going to press there is not) you will be offered the opportunity to participate. The aim of clinical trials is to improve treatment for the future, and your medical team will be able to discuss this with you in more detail. This may involve some patients in the trial using different combinations of treatment, so that doctors can assess what works best. Trials are run in several treatment centres and are strictly regulated by national organisations. Participation in clinical trials is entirely voluntary, and if you decide not to take part your child will be treated according to standard guidelines.

Food and Nutrition

Keeping your child's weight fairly stable can be a worry as he or she undergoes chemotherapy treatment mainly because losing weight may make them less able to withstand infection.

All the normal rules your family has about food and what your child should or should not eat are likely to be forgotten in your efforts to encourage your child to eat when they are able to.

Changes of taste are common during chemotherapy so children may like stronger flavours than usual – Katie craved curries – and you may find they no longer like their favourite foods. They may also be more likely to 'graze' i.e. eat less food but at more frequent intervals.

The hospital dietician can help with suggestions of ways to encourage your child to eat. You will know your child's likes and dislikes best and it is often worth giving them all their known favourites. However much this may go against your parental instinct, it is better for them to be eating high calorie foods than nothing at all. Giving your child several packets of crisps every day will probably feel wrong but over several days this may be the best way to keep their calorie intake up. If your child doesn't like the hospital food, making their favourite meals at home or, for example, buying in pizzas locally may help them to eat on a more consistent basis.

It is important that you don't feel guilty about this situation, and don't worry if they start eating the same foods again and again. Katie's appetite increased hugely, so be prepared for this. Remember that steroids are also likely to cause a significant increase in appetite which can be difficult for parents to manage.

Your child may quickly develop problems with swallowing in which case they are likely to need help with eating. You may also be referred to a speech therapist to help with this as choking or problems with swallowing can lead to infection in the lungs. You can try cutting up food into smaller pieces, thicken drinks and soups, or make juice smoothies if this helps.

Good mouth hygiene is vital as the mouth can be an area of infection so it's important to keep the mouth clean and moist.

Section 2

Positive Thinking

During the period of treatment you will have many ups and downs, as we did. Although the initial shock of the 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 may keep you awake at night particularly if treatment is slower than hoped or things don't go according to plan.

Striving to be positive about the future can help you deal with the treatment and the inevitable side effects. Support from close family and friends, and your church if you attend, can help keep your spirits up while you're on this stressful and emotional rollercoaster. Many people believe that positive thinking can have a tangible effect on how you cope with an illness and at the very least it can help maintain the stability of your child's home environment, as well as minimise the impact of the illness on the family unit.

It is vital that you try to maintain your social activities when you can as this keeps your lives as 'normal' as possible and gives you a well-earned break from the worry and stress you will inevitably feel as your child goes through the treatment process. We found that we adjusted our social activity, for example Katie's friends would come to visit instead of her going out to play, and friends and family would come to our house for dinner so that we didn't have to travel.

It can be a good idea to discuss some short-term targets for the whole family to enjoy, perhaps when you begin to work out your child's 'best days' within the treatment cycle. A family trip to the cinema or a favourite restaurant will give you some quality time together as well as distracting you from your worries, if only for a short period.

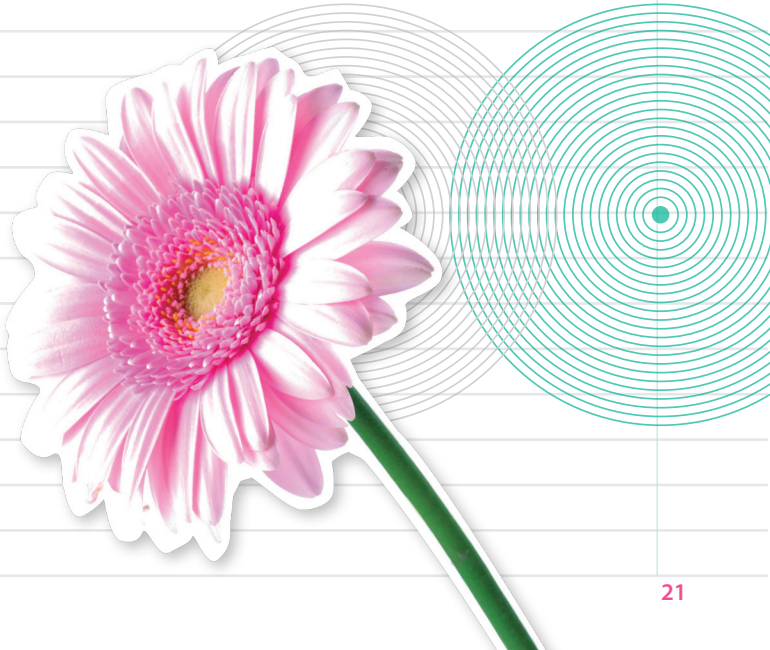
End of Treatment

Even though treatment is difficult it at least provides the assurance of being in regular contact with the hospital and taking action to treat the illness.

When Katie's chemotherapy treatment was stopped, the plan was for her to have a month away from treatment during which time we hoped she would recover some of her strength. But her condition worsened and a further MRI scan showed fluid on her brain. She had an operation to have a shunt fitted to drain this fluid away. We were then informed that although the tumour had not grown it had not reduced in size either so, because of Katie's negative reaction to the chemotherapy drug Temozolomide, our consultant advised no further treatment.

The consultant also asked us to consider Katie having a further operation to fit a PEG, a feeding tube inserted into the abdomen. We were against this idea but felt under pressure to make a decision until Katie was examined by an anaesthetist who told us she had a one in four chance of not surviving this operation. This gave us the confidence we needed to say 'no' to the PEG being fitted.

After Katie's treatment ended we were desperate and felt that we had nowhere else to turn so we started looking into alternative therapies.



Section 2

Alternative Therapies

Surveys of families affected by cancer indicate that up to 80% use some form of complementary therapy during or after the medical treatment has been given.

In the past, alternative or complementary medicine was dismissed by doctors but it is now recognised that many families – including our own – often benefit from the positive effects of treatments such as acupuncture, massage, counselling or nutritional therapies.

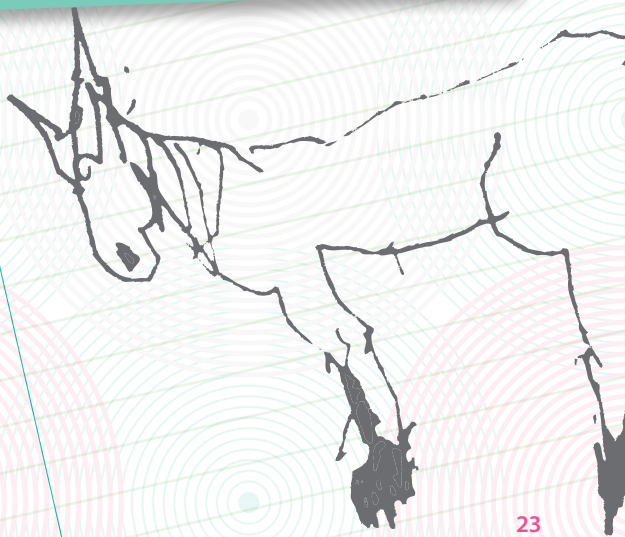
In our case, Andrew contacted a friend who knew a healer and the hospital got our fantastic local GP and outreach nurse involved. We took Katie out of hospital for a few hours the next day to see the healer and, once she returned home, we continued to travel to see the healer (a 3.5 hour round trip) seven days a week for the next six months. This man never charged us a penny for his time.

Katie soon showed a remarkable improvement and was able to chat, draw, and go to the local pub for her favourite meal, which was of course amazing to see. Katie was in much better health for a three month period but sadly she began to deteriorate once more and passed away four months later, in January 2009, having suffered respiratory failure. However we do not regret seeking out the healer as we and Katie believed that it made a significant difference to her quality of life. Every child and family is different so this decision is entirely up to you.

Never spend money online on 'miracle' cures but speak to your medical team about seeking alternative treatments if required. It is also vital that you discuss with your consultant any alternative therapies you plan to use to ensure they do not interact in any harmful way with your child's medication.

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Section 3

Hospital Stays

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. You are also likely to be admitted to hospital for your child to receive antibiotics if they have an infection or their blood count is low.

When your child is receiving chemotherapy treatment he or she is likely to feel ill for some or even all of the time. It will take a few cycles of chemotherapy to refine the level of anti-sickness drugs best for your child and it's important you let the medical team know what has and hasn't worked.

It is likely that you will want to stay with your child if he or she needs to be in hospital both to provide comfort and support and to help care for him or her. Remember your child may need to spend time in hospital unexpectedly so you might need to drop your plans at the last minute – this can be difficult and you will probably feel out of control of the situation (as we did) but we learnt that it is important you remain as flexible as possible during this stressful time.

Practicalities

The medical team will probably advise you to use rubber gloves when you help your child go to the toilet in hospital and for the first week at home, as 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. It will depend on the hospital as to whether you're advised to do this or not.

You may be in a separate room for your hospital stays or in an open ward, depending on the hospital. The rooms have additional beds for parents and in open wards there is likely to be a camp bed which you can put next to your child's bed. There may also be separate family accommodation near your hospital which you can access, such as a house supported by CLIC Sargent or Ronald MacDonald.

As treatment continues the cumulative effect of the medicine may lead to greater fatigue. You may notice that your child sits out of activities or becomes more tired in the mornings. This is the time when a disabled badge (Blue Badge) is most useful as it helps hugely with parking close to the hospital, which is often in a congested area and can be very costly. Your social worker can advise and help you fill in forms to apply for a disabled badge, as well as advise on a number of practical and financial issues, particularly if you need to take an unpaid absence from work. If you're struggling financially, don't be afraid to speak to the social worker, who can put you in touch with someone who can help.

In the winter months you and your partner may be advised to have the flu jab so that you don't risk passing it on to your child. It could prevent you from going into hospital with them when they are admitted either because you feel too ill or may pass the infection on.

Section 3

What's Needed at Home

An occupational therapist should carry out a home visit to clarify your needs. The home may need to be adapted quickly in line with the progression of the illness.

We received help with installing a barrier to prevent Katie from falling out of bed, a bannister was fitted to help Katie up and down the stairs (while she was still able to walk), then a stair climber was hired to take Katie up the stairs, and we were given items such as an inflatable ring to help give Katie a bath.

A physiotherapist may also get involved if your child is mobile – for example Katie was able to go swimming in the hydro pool at our local hospital, which she really enjoyed. She also had help from a qualified teacher while at home and this helped keep her occupied and mentally active for a short time (around five weeks).

You may decide that now is a good time to have some professional photographs of the family taken as this may feel like a positive and celebratory step at this difficult time.



Communication

As you go through the treatment process, you may feel you'd like to have a friend act as a 'communicator' (for example an outreach nurse, or a family friend who may help pass on information) with family, school and other groups. There may be many months when there is little new to say but keeping them up to date with major milestones, such as radiotherapy or surgery, helps them to continue to take a load off your mind.

It is important, if you can, to make sure that two people (either your partner or a friend) attend meetings with your consultant as it is often the case that you will each remember different pieces of information, and you may both have different questions to ask.

Remember to take your notes with you so that you ask all the questions you meant to ask.

Even when you are midway through a course of treatment you may find that you still have to break the news to acquaintances or work colleagues who may not already know about your child's illness. Try not to be upset by their reaction – you may have had several months to get used to the situation however they will undoubtedly be shocked on hearing the news for the first time.

Section 3

Siblings

As your child goes through what may be several months of treatment it is important that any siblings do not feel ignored. While they may appreciate that you could have to spend regular or long spells of time in hospital with their brother or sister, their understanding may wear a little thin if this goes on month after month. Their lives could change significantly because of their sibling's illness and they may start to feel resentful about all the attention he or she is receiving, or they may be too young to understand what is happening.

There are things you can do to help your family get through the difficult times during treatment. You and/or your partner spending time individually with your other children, perhaps taking them out for a meal or spending quality time with them when one of you is in hospital with your sick child, can help them feel less excluded. For example one of us would watch our sons play football while the other was with Katie, and we made the effort to watch a DVD with them regularly, or went for a dog walk with them so that we could chat and catch up.

If your children are at school it is very important that you keep in close contact with their class teachers in order to pick up early on any problems with school work or friends. You may be so caught up with caring for and worrying about your sick child that you don't notice another of your children is also experiencing problems. Their teacher(s) should be able to let you know about any changes in their behaviour.

You also need to think about how much information you tell your children – in the face of negative news you may not wish your other child/children to know. You will need to decide how you think they will deal with the information and whether they're old enough to be able to cope with it. We told our two sons, who were 12 and 14 at the time, about the seriousness of Katie's illness when the medical team decided that no more treatment could be given. We told Katie a few months later, although we still remained positive about her recovery.


The McKerracher Family

This is of course an entirely personal decision and will differ between families so don't feel you should be behaving in a certain way.

Section 4
The Medical Team

Section 4

The Medical Team

You will meet lots of different people in hospital and you may find this confusing at first. It is worth understanding the role of each so that you can direct your questions to the relevant person.

Your own GP

Throughout your treatment you may have little formal contact with your own GP as any queries about your child's treatment should normally be directed to your 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. Our GP helped us with obtaining local prescriptions, and was on-hand to help when Katie returned home once her treatment ended.

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.

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.

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.

Registrars and Senior House Officers

These doctors will be involved in the day to day care of your child when in hospital. Most of the tests and treatments are carried out by them under the supervision of the consultants. They may still be in training and move from one ward to another so you could 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 and will administer all the drugs they need as well as advising you on how to care for your child at home after the hospital visits. The sister or charge nurse is in charge of the ward, with staff nurses and student nurses working 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 and put in central lines, PEGs, or a shunt. The consultant surgeon liaises very closely with the consultant oncologist in your child's overall treatment plan, particularly on the timing of the 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 may visit your GP and your child's school to explain your child's condition and treatment to the teaching staff, and may also arrange to meet with your local community nurse.

Associate Specialist

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

Pharmacist

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

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 inevitable stress caused by the illness and treatment.

Dietician

Dieticians look after the nutritional needs of your child during treatment. If you are worried about your child losing weight, a discussion with the dietician may give you some ideas on different foods to try. They can also advise on other forms of nutrition, such as high energy supplements given through a nasogastric tube or a PEG.



Hospital School Teacher

During your child's time in hospital, and depending on how sick he or she is, it may be possible for them to keep up with schoolwork. The hospital school teacher will visit the ward to work with your child on a one-to-one basis to catch up on any schoolwork missed. If your child is at home and off school, the hospital teacher may also be able to visit you at home.

Dentist

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 and neck to ensure that there is little or no decay as both forms of treatment can aggravate the effect of decay on their teeth.

Occupational Therapist

An occupational therapist reviews your child's daily routine and your home to identify modifications that will help him or her cope with changes in physical ability. The OT may also be able to provide access to equipment to aid mobility – wheelchair, stair climber, shower seat etc.

Physiotherapist

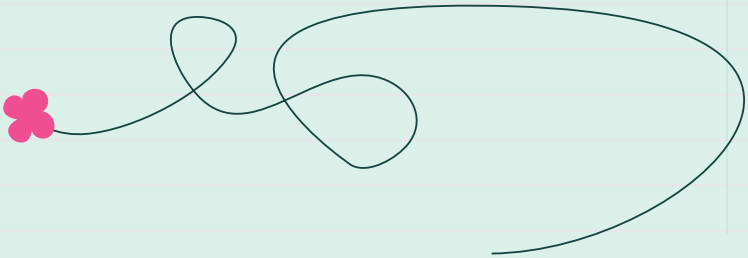
A health care professional who specialises in maximising human movement, function and potential.

Speech Therapist

Speech and language therapy is concerned with the management of disorders of speech, language, communication, and swallowing.

Play Specialist

A play specialist may be available and he or she will spend time with your child enjoying craft and play sessions which can be very therapeutic.



Section 5

The Katie McKerracher Trust



Katie McKerracher Trust

Celebrating Katie's spirit by doing good for others, in a way that Katie would have been proud of...

The Katie McKerracher Trust was set up in memory of our daughter Katie who was diagnosed with a DIPG in February 2008. Katie passed away in January 2009 and we wanted to do something constructive and positive, in her name, which would both celebrate her life and provide support for families going through the same devastating experience as we did.

We never got to know other patients and their families in the same situation as us but are in no doubt that this would have helped us hugely. We are positive that our experiences can help other children and their families deal with the impact of a DIPG, in both practical and emotional ways.

Please get in touch if you feel you need our help.

Support available

The Katie McKerracher Trust was established in 2009 and provides emotional and/or financial* support by:

- Offering financial assistance to patients to help them deal with practical day-to-day issues
- Meeting with patients and families to help them understand what might happen, share our experiences, and answer any questions they may have
- Providing some financial assistance to access alternative healing or therapy if appropriate
- Working with health professionals to seek to improve treatment for DIPG patients

* Please note that the only pre-condition for applying for a monetary grant is a copy of the letter of diagnosis (this is a requirement in the Trust's constitution).

Examples of things we have helped with so far are travel expenses, equipment to make it easier to move in/out of cars, help with household appliances, and days out for the family.

Dance grant

The Trust has maintained links with the Lesley MacFarlane School of Dance, in Hawick, and we remember Katie's love of dancing by awarding an annual grant to a dancer from the Borders area who is continuing their studies into higher education.

Katie's Tartan

At the beginning of 2008 Katie and her friend Iona were going through a spell of acting out their own fashion shows whenever they could persuade us to watch! Designer Annie Stewart of Anta created a tartan especially for Katie so it seems very appropriate that Katie now has her own tartan, which has already graced several catwalks.

Anta also sells a range of Katie McKerracher items (at their shops in Edinburgh and Ross-shire) with 5% of the proceeds from all their sales going to the Trust. If you would like to know more about this contact Anta on:
Email: www.anta.co.uk / sales@anta.co.uk
Telephone: Edinburgh 0131 225 9096 /
Ross-shire 01862 832477

Fundraising Events

The Trust holds regular fundraising events to secure the future of the charity and enable us to help more families long-term.

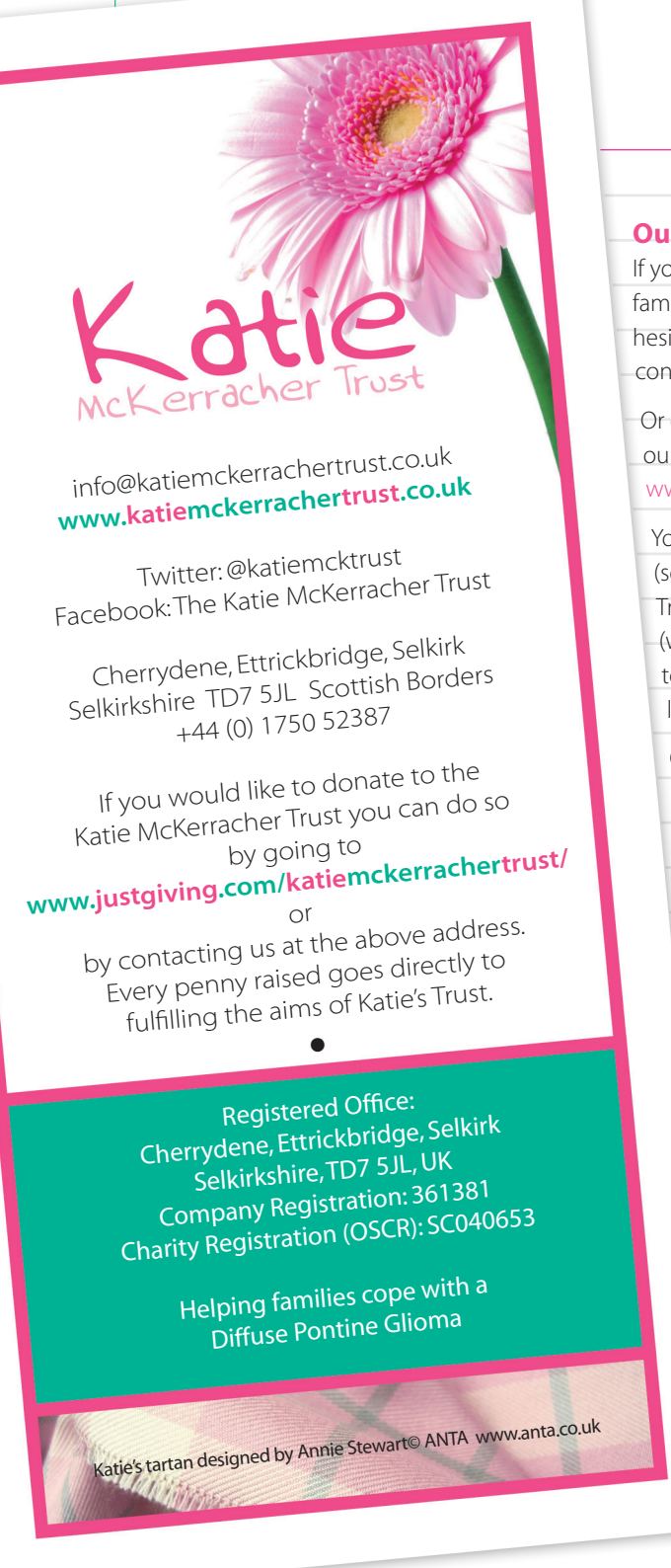


Katie's Tartan



Hebridean Cycle Challenge


Katie's Tartan Launch



Our Contact Details

If you need support – or know a family that does – please don't hesitate to contact us using the contact details opposite.

Or complete the Enquiry Form on our website:
www.katiemckerrachertrust.co.uk

You can also 'like' us on Facebook (search for The Katie McKerracher Trust) and follow us on Twitter (www.twitter.com/katiemcktrust) to keep up to date with our latest news and events.

Company Registration: 361381

Charity Registration (OSCR): SC040653

Section 6
Glossary & Useful Websites

Section 6

Glossary of Terms

Anaemic: Caused by a decrease in red blood cells, or less than the normal quantity of haemoglobin in the blood.

Antibiotics: Medicine which kills or slows down the growth of bacteria.

Alternative therapies/Complementary medicine: Any healing practise which does not fall within the realms of conventional medicine e.g. spiritual healers, acupuncture, homeopathy, reflexology etc.

Biopsy: A small piece of tissue taken from any part of the body in order to examine it under a microscope to make a diagnosis.

Blood counts/Full Blood Count (FBC): Gives the medical team information about cells in the patient's blood (haemoglobin, white cells and platelets).

Blood transfusion: Giving blood (concentrated red blood cells) into the patient's circulation – used when the haemoglobin is low. This is administered via a central line or an IV cannula.

Brain stem: Part of the brain that is responsible for numerous vital functions, including the control of breathing. Nerves pass through the brain stem to the rest of the body.

Cancer: Abnormal growth of cells (primary tumour) which may spread to other sites and create secondary tumours.

Cell: The living units from which animal and plants are built i.e. blood cells, brain cells. They are so tiny that one million cells would fit on a pinhead.

Chemotherapy: Drug treatment to kill cancerous cells.

Diagnosis: The exact name and type of the patient's illness.

Diffuse Intrinsic Pontine Glioma: An inoperable tumour in the brain stem.

- **Diffuse:** To spread
- **Intrinsic:** Belonging to or lying within a given part
- **Pontine:** Part of the brain stem
- **Glioma:** A type of tumour that starts in the brain or spine

Disease: An abnormal condition affecting the body or an organism.

General anaesthetic: A drug which brings about a reversible loss of consciousness.

Haemoglobin: The part of the red blood cell responsible for carrying oxygen round the body.

Hormone: A chemical released by a cell or a gland in one part of the body that sends out messages which affects cells in other parts.

Hydro pool: Some hospitals have a small swimming pool operated by the physiotherapy department, used to help patients regain mobility.

Medication: A pharmaceutical drug also referred to as medicine.

MRI/CT Scans: Scans which provides a detailed picture of what is going on inside the brain/body.

Nasogastric tube: A medical process involving the insertion of a plastic tube through the nose, past the throat and down to the stomach.

Nausea: Feeling sick.

Oncology: The study, diagnosis and treatment of tumours, especially cancers.

Paediatric Oncology: The branch of medicine which specialises in the study and treatment of child cancer.

PEG: Percutaneous Endoscopic Gastronomy. A tube is inserted into the stomach through the abdominal wall to provide nutrition.

Platelet: A tiny cell in circulating blood which aids blood clotting.

Pneumonia: An infection of the lung.

Primary tumour: The tissue or organ in the body where the tumour originally started growing.

Prognosis: An estimate of the outcome of the disease based on the patient's current condition and accumulated medical knowledge about the disease and the treatment best for it.

Protein synthesis: The process in which cells build proteins

Pyrexia: Fever/abnormally high body temperature.

Radiotherapy: Treatment with x-rays, or radium cobalt and other radioactive substances, which aims to stop growth of cells.

Section 6

Red blood cell: The oxygen carrying cell in the blood which contains the pigment haemoglobin. Produced in the bone marrow.

Respiration: The process of breathing.

Respiratory failure: Oxygen and/or carbon dioxide levels cannot be maintained within the body so the volume of air flowing in and out of the lungs is not matched with the flow of blood to the lungs.

Secondary tumour: Metastasis – the spread of a malignant tumour from its original site through the bloodstream to one or more other tissues.

Sepsis: Any form of infection.

Shunt: A passage device allowing fluid to move from one part of the body to another. Within this context a shunt between the ventricles (fluid-filled chambers in the brain) to the peritoneum (the cavity within the abdomen) may be required. This is known as a Ventriculo-peritoneal shunt.

Steroids: Drugs which are used (in this context) to help reduce swelling and are particularly useful to help symptoms due to raised intracranial pressure (fluid not draining properly within the brain).

Symptoms: When a patient notices a departure from normal feeling or function, usually indicative of the presence of an illness or disease.

Terminal illness: A disease which cannot be adequately treated or cured and therefore leads to the death of the patient usually within a short space of time i.e. a disease which will end the life of the sufferer.

Temperature spike: When the body temperature suddenly goes up.

Treatment plan/protocol: The treatment plan, or the protocol, is a plan for the best combination of radiotherapy, chemotherapy and any other treatment needed for your child.

Tumour: An abnormal growth of cells.

White blood cells: Cells in the blood which are most important in fighting infection.

Helpful websites

CLIC Sargent www.clicsargent.org.uk
Clic and Sargent Cancer Care for Children merged in 2005. The charity offers individual support to families affected by cancer through clinical, emotional and financial services in hospital, at home and in the community across the UK.

Cancer BACUP www.cancerbacup.org/cancertype/childrenscancers
Cancer BACUP's mission is to give cancer patients and their families the latest information, practical advice and support they need to reduce the fear and uncertainty of cancer.

TIC www.click4tic.org.uk
A website designed for teenagers to give advice and support on how to cope with cancer.

CCLG www.cclg.org.uk
The CCLG is a UK-based association of healthcare professionals involved in the treatment and care of children and younger teenagers with cancer.

CHAS www.chas.org.uk
Children's Hospice Association Scotland (CHAS) is a Scottish charity which provides the only hospice services in Scotland for children and young people with life-shortening conditions. CHAS runs two children's hospices in Scotland (Rachel House in Kinross, and Robin House in Balloch).

Children's Hospices UK www.childhospice.org.uk
For information on finding your local children's hospice, wherever you live in the UK.

Samantha Dickson Brain Tumour Trust www.braintumourtrust.co.uk
The UK's leading charity dedicated to brain tumour research and patient information and support.

Thanks

We have a number of people who have helped us in some way to produce this very important booklet and we feel we would like to mention. Our thanks go to:

- **Drs Donald** and **Lucille Macleod** for confirming to us the need for both the Katie McKerracher Trust and this booklet.
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Finally a **huge** thank you to all our family and friends, and indeed lots of people who we don't even know, who have all organised fundraising events and helped put the Trust in its current financial position, enabling us to help many more families.

Notes

Disclaimer: The information is provided on the understanding that this booklet should not be wholly relied upon when making any related decision. The information contained within this booklet is provided on an "as is" basis with no warranties expressed or otherwise implied relating to the accuracy of the information. We cannot provide any representation that this booklet will be error free. August 2011.

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