A BOOKLET FOR PARENTS

3rd Edition - Updated for the Website in August 2009 to reflect the new International Neuroblastoma Risk Group Staging System

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Acknowledgements are on page 57.

For Notes

The Booklet

- This booklet is divided into two parts:

(1) An outline describing the features of neuroblastoma.
(2) A discussion of your feelings as parents coping with a child with neuroblastoma in the family.

- Please remember that if your child is just beginning treatment, there may be information in this booklet that has not yet been discussed with you. Alternatively, if your child's treatment has been completed, points in this booklet may be different from your own experiences.

- At no time is this booklet meant to provide an alternative to personal discussion with the treatment team (*used throughout the booklet as shorthand for the many specialist doctors and nurses treating your child at the main treatment centre*) caring for your child. It is meant as a back-up to the information you have been given already, or will be given in the future. It will act to remind you of discussions you have with the treatment team.

- You should bear in mind that any information about neuroblastoma in a booklet such as this must necessarily be general. Every child is an individual and your own child's case must always be discussed with the treatment team caring for your child.

- Part two of the booklet discusses feelings you may encounter in coping with neuroblastoma. Early on in treatment you may wonder how you will manage. Even if you have been through treatment, it may be useful to know that your feelings are not uncommon. Much of what is contained in Part Two is common to anyone who has a child suffering from any form of cancer.

Introduction

- If you have been told recently that your child is suffering from neuroblastoma, it may be very difficult to grasp and remember what has been said as you may feel bewildered, frightened and shocked.
- It is probable that you have never heard the word 'neuroblastoma' before and may not have even realised that children suffer from tumours. Perhaps, like many people, your ideas about cancer have come from the media, or from older relatives in your family who may also have been treated for it. Cancer is a disease that leads to many 'old wives tales', and it is important that you try very hard to bear in mind the treatment team's assurance that many children's cancers, including neuroblastoma, differ a lot from adult tumours.

- Neuroblastoma is a tumour almost exclusively of childhood and there is no exactly comparable tumour in an adult. It has its own treatment that is different from any treatment undergone by anyone else you know who has had cancer.

- In recent days, you may have met a great many new faces, heard a lot of strange medical terms and your child may have undergone a series of puzzling and worrying investigations. All the hospital staff involved with your child understand that you may need some time to absorb what has happened, and what you are being told about their treatment. You must ask if you do not immediately understand something. You may need to ask some questions several times and, if so, don’t feel that people imagine you are either foolish or unintelligent. At a time like this, it is very common to find it difficult to take in or remember information that you are given.

- If the language used by the treatment team is not your first language, and you have difficulty in understanding the language used, arrange for a relative or friend to be present who can

interpret. If you cannot find anyone to help, an interpreter can be arranged via the Social Work Department or through other contacts within the hospital.

- Many parents cannot think of any questions to ask when a doctor is there, but think of all sorts of things as soon as they have gone. It is a good idea to write down things that you especially want to know, so that you can discuss your questions at the next opportunity. There is space on page 2 of this booklet for your notes.

- Some people are shy of questioning or approaching members of the treatment team, feeling that they are too busy. They probably are very busy, but they are caring for your child and want to know of your concerns and discuss them with you.

- If a particular moment is inconvenient, it may be suggested to you that later on the doctor and perhaps other members of the team could sit down with you and go over your concerns. This is not to ignore your urgent worry, but to provide a setting and a time when unhurried discussion can take place. It may be that the doctor has to wait for results of certain tests before any realistic discussion can take place, but it is understood that such a time of waiting is a very difficult and anxious one for you and your family.

Neuroblastoma

- Neuroblastoma is a tumour arising from particular nerve cells which run in a chain-like fashion up the back of the child's abdomen and chest and into the skull following the line of the spinal cord (neuro = nerve, blastoma = collection of tumour cells). The most common site for the tumour to grow is the abdomen (tummy). About 50% start in the adrenal gland above the kidney. Some tumours grow at the back of the chest and occasionally even higher up towards the neck. Much more rarely, the tumour may start in the brain itself.

- The site of the tumour may cause different symptoms at the time of diagnosis. For example, a tumour right at the back of the abdomen, which has grown to press on the spinal cord, may cause a variety of symptoms including an unsteady walk or difficulty in passing urine. A child who has a tumour in the chest may have an initial problem with a chest infection, cough or fluid in the lung, which may need treatment before the neuroblastoma itself is tackled. Many children have little in the way of symptoms. Perhaps they have seemed 'off colour' for a little while or have had a loss of appetite, vague aches and pains or sweating. Unless a parent or a doctor feels a lump, while bathing, dressing or examining the child, a diagnosis of neuroblastoma may not be initially considered.

- Only about 80-90 children per year are diagnosed with neuroblastoma in the UK. It is possible that many of the symptoms your child presented with are similar to those of the more common, non-serious childhood illnesses. Many parents wonder if they or a doctor should have noticed something sooner, but because this is such a rare disease it is likely that neither a family doctor nor a Paediatrician will ever see a child with neuroblastoma in a lifetime of practice. Thus, the diagnosis is rarely suspected if only fairly vague symptoms are present.

- Once neuroblastoma is suspected, your child will be referred to a specialist child cancer treatment centre for diagnostic

tests and a treatment plan. Although neuroblastoma is rare, these centres will see the majority of children who are diagnosed and thus they build up and maintain a body of knowledge and expertise about the tumour and its treatment. Such an approach would hardly be possible in a small hospital where neuroblastoma is never treated.

Diagnosis

- The diagnosis of neuroblastoma is usually confirmed by tests at the specialist treatment centre. Tests your child will most probably undergo are clinical examination (the doctor's physical examination), blood and urine tests, special scans, X-rays and bone marrow tests, as well as a 'biopsy' of the main tumour mass. All of these may seem frightening to both you and your child, but the reason for having each test will be discussed in detail.

1. Tumour Biopsy

A small piece of tumour is often taken for examination. This test is known as a biopsy. It involves an operation where your child has a general anaesthetic and a piece of tumour is taken out through a small cut (incision) in the skin. Alternatively, a piece of tumour may be drawn up through a needle; this procedure is known as a 'needle biopsy'.

2. Blood Tests

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

3. Urine Tests

A simple special test in the diagnosis of neuroblastoma measures something called the Vanillyl Mandelic Acid. You may hear this test referred to as either the 'VMA' or 'urine catecholamine' test. VMA is a chemical found in the urine in raised levels when a child has neuroblastoma and this is a good indicator to the Paediatric Oncologist of the diagnosis.

4. Scans and X-Rays

Ordinary X-rays, ultrasound tests and special scans give confirmation of the presence of the main neuroblastoma (referred to as the 'primary') and also to show if there are any other tumour cells which have spread to other parts of the child's body ('secondary tumours' or 'metastases').

(a) ***X-rays*** -You are probably familiar with ordinary X-rays.

(b) ***CT scan*** - The CT scanner (the initials stand for Computerised Tomography) takes multiple X-ray films and these are 'converted' by a computer into a kind of 3D view of either the whole body or part of the body under examination.

(c) ***Ultrasound scan*** - The ultrasound scan will be a familiar procedure to all mothers who had this performed during their pregnancy. It works by passing a 'sonar' (like a small microphone) 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 Radiologist and Oncologist can see the outlines or shadow of normal organs and of any tumour or abnormality inside the body.

(d) ***mIBG scan*** - mIBG stands for 'meta-iodobenzylguanidine'. This substance is naturally taken up by neuroblastoma cells. mIBG contains radioactive material (which is not harmful) and is given by injection into the blood stream. When mIBG accumulates in the neuroblastoma cells, the radioactive material can be detected by means of a special type of X-ray machine called a gamma camera scanner. This type of scan is obviously a very useful diagnostic tool, giving a complete picture of the whereabouts of any tumour cells in the body. mIBG may also be used later on in the child's treatment as a way of offering so-called 'targeted radiotherapy'.

(e) ***Bone scan*** - A bone scan involves an injection of a small amount of radioactive dye (which is not harmful) into a vein, usually in the hand or forearm. The radioactive material gathers in bones where the tumour has spread and these can be seen when pictures are taken on a gamma camera. Some centres may use a mIBG scan as a way of obtaining the same information as that obtained by the bone scan.

(f) ***NMR/MRI scan*** - This test is referred to by either the initials

NMR (Nuclear Magnetic Resonance) or MRI (Magnetic Resonance Imaging). The scan relies on magnetism and thus radiation is not used. It takes longer than at CT scan and is quite noisy. There are no known side effects to this type of scan.

- Apart from the need for an injection of 'contrast' during some CT scans and the injection of dye for a bone scan or mIBG scan, none of the above investigations are painful to your child, but it is appreciated that they may feel unsettled or frightened. Some of the scans require that your child remains still for quite some time and to assist in this sedation may be given. An anaesthetic may be needed for some children to have some of the tests.

5. Bone and Bone Marrow.

The most common sites to which neuroblastoma cells spread are bones and the bone marrow. To detect tumour cells in the bone, your child will probably undergo either a bone scan or a mIBG scan (see above), or both.

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 very small piece of the bone at the site where the marrow is drawn out. To make sure that the test is as accurate as possible, aspirates and trephines may be taken from more than one site; usually from the hip bones on either side of the body. The child will always be given an anaesthetic before these tests.

- It may take several days for the tests to be completed. Undergoing these tests and waiting for results is an exhausting time, full of anxiety. However, exact assessment of the extent of your child's disease before beginning treatment is very important. The results obtained can affect the type and length of treatment that will be given to your child.

Tumour 'Staging'

Doctors recognise several special categories of neuroblastoma that are grouped into different 'Stages'. Staging means how far the tumour has spread in the body. The different stages of neuroblastoma have different treatments, as they carry with them different risks. Other factors that may affect your child's prognosis are their age and the results of several laboratory tests that will be carried out during the initial investigation period.

For many years the International Neuroblastoma Staging System (INSS) has been used to assess individual children and these descriptions are likely to continue for some time alongside a newly introduced International Neuroblastoma Risk Group Staging System (INRSS). The new system is aimed at getting a better match between the risks and side-effects of therapy (treatment) with the risk of disease. As these new staging definitions are adopted worldwide it will also be possible to get a more accurate comparison of the effectiveness of different treatment strategies. The approximate INRSS stage is shown in brackets against the INSS stage below.

1. Stage 1 Neuroblastoma. **(INRSS stage L1)**
This means that the tumour is fairly small and confined to one site. It has not spread anywhere else in the body and is able to be removed completely by an operation. This type of tumour is usually curable by surgery alone.

2. Stage 2 Neuroblastoma. **(INRSS stage L1)**
As with Stage 1, the tumour is confined to one site and has not spread to distant parts of the body. However it may be larger than a Stage 1 neuroblastoma and, at operation, it may be more difficult to remove completely. Sometimes a lymph node or some glands near to the Stage 2 neuroblastoma may also have been affected by the tumour. Stage 2 neuroblastoma is usually treated by surgery alone but, depending on the site and results of certain tests, additional treatment such as chemotherapy (see page 15) may be needed.

3. Stage 3 Neuroblastoma. (INRSS stage L2)
This stage of tumour is also confined to the primary site in that it has not spread to other distant parts of the body. The tumour may be very large and said to have crossed the 'mid-line' of the body. This means that the tumour has grown right across the child's abdomen or chest from the original side where it began. In the case of Stage 3 neuroblastoma, drug treatment will be initially recommended to try to shrink the tumour for subsequent surgical removal. After the operation, radiotherapy may be given.

4. Stage 4 Neuroblastoma. (INRSS stage M)
This means that the primary tumour may be of any size, but some neuroblastoma cells have broken away and spread to other organs of the body, most commonly bones, bone marrow or liver. Drug therapy will be recommended for a Stage 4 neuroblastoma. This has two aims:

(a) To kill the tumour cells that have spread to different body organs.
(b) To shrink the primary tumour for later removal by an operation.

- After surgery, further drug therapy is given, using very large doses of chemotherapy (see page 15). After this 'high dose chemotherapy', the next part of treatment may involve radiotherapy which is treatment using high strength X-rays. Finally fairly gentle treatment is given to mop up the few remaining tumour cells that may be left in the body.

5. Infants with Stage 4 Neuroblastoma. (INRSS stage M)
Most infants under one year of age who present with Stage 4 neuroblastoma have less 'aggressive' neuroblastoma than that occurring in older children. Therefore, they may receive a less intensive course of chemotherapy than a toddler or older child.

6. Stage 4S Neuroblastoma. (INRSS stage MS)
This is a special type of tumour found in very young babies, under one year old. The tumour cells may have spread beyond the

'primary' site to other parts of the body, but the cells usually behave in a less aggressive fashion than in the older child. The tumour may shrink and disappear without treatment. Alternatively, low doses of either radiotherapy or chemotherapy may be given to encourage the tumour to shrink. The sites affected by Stage 4S neuroblastoma are typically liver, skin and sometimes bone marrow. When this pattern is noted, the Oncologist may feel fairly confident that the child will get better with no treatment or very little treatment.

Sometimes, some weeks or months after diagnosis, surgical removal of the 'primary' tumour will be recommended. Also, sometimes the tummy may swell so much with the tumour that chemotherapy is needed to shrink the tumour and relieve the pressure in the abdomen. Very occasionally, a baby with a Stage 4S neuroblastoma may later develop signs and symptoms of the more 'aggressive' Stage 4 neuroblastoma. The cells typically appear in the lymph glands or bones, and in this case the doctors may then decide to give drug treatment.

7. Ganglioneuroblastoma.

Ganglioneuroblastoma is another type of tumour, but a close 'relative' of neuroblastoma. It can present in any age group, but the cells of this tumour are more 'mature' (i.e. less likely to spread) than those of the ordinary neuroblastoma. Like neuroblastoma, ganglioneuroblastoma Stages 1, 2 and 4S, may be cured by surgery alone. Other stages will need chemotherapy in addition to surgery.

- You can be assured that if it is possible to treat your child with surgery alone or, very rarely, not to give any treatment at all, they will still be watched and examined very closely for many months.

- No one wishes to subject your child unnecessarily to the possible side effects of treatment. If it is considered that the risk of the tumour cells spreading is very small, or that the tumour may go away on its own, minimal treatment will be advised.

- It is most common, however, for a neuroblastoma to present as Stage 3 or 4 in the toddler or older age group, and this usually requires strong drug treatment from the outset.

- Doctors and scientists are continuing to learn more about neuroblastoma. Recently, they have discovered that special biological tests can indicate how aggressive a particular neuroblastoma is likely to be. Your child's treatment may thus depend on the results of these special tests, carried out on a sample of the tumour. The results take a few weeks to come back to your doctor as they are carried out in a special laboratory.

Treatment

- There are three important types of treatment that are used in cancer therapy: Surgery, Radiotherapy and Chemotherapy.

1. Surgery.

This is an operation to remove the tumour if it is possible. Surgery may be involved at a later stage of treatment, often after several courses of chemotherapy have been given to shrink the tumour so that it can be more easily removed by the Surgeon.

2. Radiotherapy.

This is treatment with special X-rays to try and kill the tumour cells. It is carried out by directing X-rays at the tumour from outside the body.

- Both surgery and external radiotherapy are treatments which can only deal with tumours in one specific part of the body.

3. Chemotherapy.

This is the main treatment in Stage 3 and 4 neuroblastoma.

- Once the diagnosis of neuroblastoma is confirmed, the site, stage and sometimes the special biological test on the tumour will guide the Oncologist in charge of your child's treatment as to the very best protocol (treatment regimen). The suggested treatment will be discussed fully with you.

- For Stages 3 and 4 neuroblastoma, the general pattern of treatment in most European centres is to give chemotherapy to destroy neuroblastoma cells throughout the body. After a period of chemotherapy, the position and site of the tumour and any metastases will be reassessed carefully by CT scan, bone marrow examinations, bone scan and mIBG scan.

- Surgical removal of the primary tumour will then be attempted. Very occasionally, even if the main tumour has shrunk

down very well, it may be near the site of main blood vessels or delicate body organs that would make surgery more complicated. In this case, it may be suggested that the Surgeon does not attempt to remove the tumour.

- In children with Stage 3 neuroblastoma, after surgery, radiotherapy to the site of the primary tumour may be given, together with more chemotherapy. This will be fully explained to you by your child's Oncologist and Radiotherapist.

- After surgery, children over the age of one with Stage 4 neuroblastoma undergo further treatment with 'high dose chemo-therapy'. The drug or drugs used in this type of therapy may differ from patient to patient. Because the treatment is extremely strong, a child may need to be in hospital for a period of about four to six weeks and be nursed and cared for in an isolation cubicle. This treatment will lower the blood count for a long time during which time the child will be prone to life threatening infections and bleeding. To shorten the period when the blood count is low, children undergo a procedure known as autologous stem cell rescue.

- This means that before high dose chemotherapy, 'stem cells' are collected (harvested) from your child. Stem cells are very special cells found in the bone marrow that act as 'mother cells' for all the other blood cells. They can therefore help a child grow a new marrow when their old marrow is destroyed by the high dose chemotherapy. These stem cells are given back to your child after the high dose chemotherapy to allow the bone marrow to recover. The stem cells come from your child's bone marrow but are actually collected (harvested) from the blood using a machine. A special tube (catheter) called a Vascath, is put into your child under general anaesthetic. This catheter allows blood to be sucked into the machine through one tube of Vascath. The machine then collects the stem cells and returns the rest of the blood back to your child through the other tube of the Vascath. The stem cells are then frozen and stored and given back to your child after the high dose chemotherapy. The harvesting procedure

takes about 3-4 hours once a day. Usually two to three days harvesting are required. This procedure is painless and has very few effects. Harvesting is performed 10 to 14 days after a course of chemotherapy. Also, to increase the number of stem cells in the blood before harvesting, a special drug called G-CSF is given to your child. This drug helps the stem cells to move out of the bone marrow and into the blood for harvesting. G-CSF is started a few days after chemotherapy and is given on a daily basis until the harvesting is finished. The whole of the harvesting procedure will be discussed in detail with you by your treatment team.

- Sometimes, as an alternative to a stem cell harvest, some children may have stem cells collected straight from the bone marrow in a procedure called a bone marrow harvest. This process is performed under anaesthetic and is very similar to a bone marrow aspirate described earlier. The bone marrow is then stored like stem cells and given back to your child after the high dose chemotherapy.

- After the high dose chemotherapy, children over the age of one with Stage 4 neuroblastoma will then receive radiotherapy to the site of the primary tumour, usually the abdomen (tummy). This will be fully explained to you by your child's Oncologist and Radiotherapist. Radiotherapy is used to mop up any tumour cells that could not be removed by surgery.

- For children with Stage 4 disease, further relatively gentle treatment is given after recovery from the high dose treatment and radiotherapy. This is given as a 'mopping-up' procedure trying to 'differentiate' (to turn from cancerous to non-cancerous) any remaining tumour cells that may be present. At present this 'gentle treatment' consists of a drug called Retinoic Acid although other treatments, such as a drug call 'GD2 antibody', are being investigated. This ‘mopping up’ treatment will be fully explained to you by your doctor.

Central Line

- If your child is going to get chemotherapy, a central line will be inserted. The other names for this device are: Hickman Catheter, Broviac Catheter, Central Venous Catheter or Long Line. Some units also use their own pet names for Central Lines (like Wiggly) to make the line more 'child-friendly'.

- A central line is a tube that is tunnelled under the skin on the chest and into one of the large veins leading to the heart. It allows treatment including chemotherapy and other drugs to be given safely and blood to be sampled. The tip or end of the central line sits in the large vein going into the heart or in one of the heart's chambers. It is quite safe for it to be in this position and the veins and heart continue to work normally. The other end of the central line comes out of the skin on the chest. The line has a "cuff" which lies under the skin and encourages scar tissue to form around it, holding the line in place.

- There are different types of central lines which may have one, two or even three tubes fixed together. They may look slightly different but all work in the same way. The central line can stay in place throughout your child's treatment. This may be months or can be years, depending on the length of each child's treatment.

- Before the line is inserted, a nurse, doctor or play specialist will take time to explain to you and your child what a line is, how it is inserted and what this will mean.

- The central line is put in under general anaesthetic in theatre. Your child will have a small cut in the neck (where the line is positioned). This wound will have dissolvable stitches under the skin. The whole procedure takes about 40 minutes. Allowing for recovery time from the anaesthetic, children are usually away from the ward for about one and a half hours.

Port (A Different Style of Central Line)

- In some children a somewhat different type of central line called a Port (e.g. 'Port-a-cath') is used to give drugs and take blood. A Port is a completely implantable central venous catheter system. It is different from other lines in that it has no part exposed outside the skin.

- A Port consists of a stainless steel chamber (some Ports have two chambers) with a silicone membrane which is placed under the skin on the chest and has a tube attached that sits in one of the large veins leading to the heart or in one of the heart's chambers. As with other lines, it is quite safe for it to be in this position and the veins and heart continue to work normally. When not in use, the Port just looks like a bump under the skin.

- In order to use the Port, a special needle called a Gripper Needle is put through the skin into the chamber of the Port. This does not hurt as much as you may think, as often the skin over the Port is somewhat numb after the Port is put in. However, anaesthetic cream ('Magic cream') can be put on the Port before the needle is inserted. The Gripper needle that goes into the Port has a short extension tube at the other end from which blood can be taken.

- The Port can stay in place throughout your child's treatment. This may be months or can be years, depending on the length of each child's treatment. Before the Port is inserted, a nurse, doctor or play specialist will take time to explain to you and your child what a line is, how it is inserted and what this will mean.

- As with other lines, the Port is put in under general anaesthetic in theatre. The whole procedure takes about 40 minutes. Allowing for recovery time from the anaesthetic, children are usually away from the ward for about one and half hours.

Side Effects

The main side effects of chemotherapy are:

1. Nausea and Vomiting

This may occur when the drugs are given or after a delay of a day or so. The vomiting caused by some drugs may last for a number of days. Most children are affected to some extent. It seems that babies and very young children have less nausea and vomiting than older children. Over the last few years, several new anti-sickness drugs have made this side effect less severe than in the past.

2. Temporary Hair Loss

This is the most visible side effect. It will begin soon after starting treatment, perhaps in two weeks, and will usually continue until the whole treatment plan is completed, when the hair grows back quite quickly and normally. The idea of hair loss is usually very upsetting to parents and, of course, quite a shock to your child.

- Most children quickly get used to their appearance and parents have often remarked that once their child's hair is lost it does not seem to bother the child at all. Some older children may like to have a wig for special occasions. However, most children do not want to bother with this and wear a scarf, hat or nothing at all.

3. Depression of the Blood and Bone Marrow

Normal parts of the blood, the neutrophils which fight bacterial infections, and the lymphocytes which combat virus infections, are damaged by chemotherapy and are, therefore, low in number. This means that your child is at risk of getting infections during the course of treatment, a number of which are caused by the 'germs' that normally live harmlessly in a child.

- The blood cells are not killed permanently. However, after each course of drug treatment their number becomes very low for some days, but then new ones begin to grow again.

- The other parts of the blood, the platelets and red cells, are reduced in number by the chemotherapy. If the platelets become low, then your child is at risk of bleeding more easily. If, for example, your child has a troublesome and prolonged nosebleed whilst their platelets are low, a platelet transfusion will be given. Also, your child may become anaemic because of low numbers of red cells. If this happens, they will receive a blood transfusion.

- The amount of haemoglobin (number of red cells), the number of platelets and the number of neutrophils in the blood is referred to as the 'blood count'. It is usually necessary to have a certain number of neutrophils and platelets before beginning each course of treatment with drugs. Therefore, the blood count is checked before starting chemotherapy. It is the recovery time of the blood cells that determines the minimum length of time between courses of chemotherapy.

- If your child is receiving an intensive drug regimen, the drugs will usually be given according to the protocol, whatever the blood count. This may mean that your child's blood count is low for much of the treatment and consequently will need to be under close observation at all times for signs of infection, which would then be treated swiftly with intravenous (IV) antibiotics.

- The reason that the hair cells and the blood cells are particularly affected by chemotherapy is that they are cells that multiply quickly. Neuroblastoma cells, in common with other cancer cells, divide very rapidly and chemotherapy is designed to kill rapidly dividing cells, so the drugs kill off many of the blood and hair cells, just as they do the cancer cells.

4. Weight Loss

Both neuroblastoma and chemotherapy may cause weight loss. If this occurs, your child's doctor will consider different methods of

providing adequate nutrition. This may be by dietary supplements (such as milkshakes and calorie powders), feeding through a tube passed via the nose into the stomach, or by feeding into the vein using the long line - this is called total parenteral nutrition (TPN).

5. Damage to the Kidneys and Hearing

Some drugs, such as cisplatin, can potentially damage the kidneys and also affect your child's hearing. Therefore, your child will undergo regular hearing tests (audiograms) as well as tests to measure how well the kidneys are working (the 'glomerular filtration rate' (GFR) test). In this test, an injection of radioactive substance (not harmful to your child) is given into a vein in the hand or arm. Blood samples are then taken.

The substance should be steadily flushed out of the body through the kidneys and the level of the substance remaining in your child's blood stream is a good indication of how well the kidneys are doing their job. If the kidneys were not functioning well, as a side effect of chemotherapy, this would be noted and the chemotherapy adjusted if necessary.

6. Fertility

Parents are also usually concerned about the effects of chemotherapy on their child's potential fertility (ability to have children). A very long-term outcome of present treatments for neuroblastoma is difficult to predict, but, for example, it is known that the drug cyclophosphamide, particularly when given in high doses, is usually damaging to fertility. However, this side effect has to be weighed against the potential benefit of using cyclophosphamide, as it is still considered to be one of the most important drugs for treating neuroblastoma.

Clinical Trials

- All children being treated for neuroblastoma at the main centres in the United Kingdom and Europe are automatically taking part in what is known as a 'clinical trial'. In the United Kingdom these main centres belong to the Children's Cancer and Leukaemia Group (CCLG).

- If you have any queries about 'new' drugs, treatments, etc., which you may have heard about in the media or from friends, do discuss these queries with your child's treatment team.

- You may feel, very naturally, that you want to explore every avenue for your child and do not want to settle for just one centre's advice about treatment.

- Perhaps, alongside the doctor's treatment, you want to do everything possible yourself for your child, through the use of one of the alternative therapies: herbal medicine, faith healing or special diet, for example.

- Talk things over with the Oncologist, who will not be offended by your wish for a second opinion or discussion about alternative therapies, as long as these strategies do not cause stress or harm to your child.

- The Oncologist will be able to reassure you though, that because paediatric oncology, and especially the treatment of neuroblastoma, is such a small and specialised area, all the doctors involved in it tend to know one another and meet frequently. They are naturally aware of the latest research in the field. Therefore, if a new treatment were developed, anywhere in the world, it is highly probable that your child's doctor would know of it and be able to discuss it with you.

- 'Clinical trial' is a worrying term to some parents who feel that their child is somehow being experimented on or being used

as a 'guinea-pig'. This is not at all the case. All aspects of your child's treatment will be fully discussed with you. The term 'clinical trial' means that the doctors involved in your child's treatment are trying to measure, consistently and reliably, information about the effects and results of treatment on your child and other children with neuroblastoma, as information is accrued over the years.

- The present treatment regimens are themselves the result of previous trials. As soon as a particular treatment seems to be more effective, or if a drug appears to be causing worrying side effects, all the doctors whose patients are taking part in the trial will know about it because they meet regularly at international meetings, and are constantly in touch with one another's work and research.

- Clinical trials may also involve the comparison of different treatments where it is simply not known whether one drug or procedure is more effective than another.

- Many centres, as a result of constantly evolving research, are now developing procedures that it is hoped will be used in the future treatment of neuroblastoma. After exhaustive tests in the laboratory regarding safety and side-effects, and after gaining the approval of each hospital's Committee of Medical Ethics, some of these procedures are now ready to be used in treatment.

Informed Consent

- Before your child is asked to take part in a clinical trial the treatment team will explain what the trial is aiming to achieve, and the risks and benefits of taking part in it. It will only be after you have had the trial fully explained and had time to consider the matter that you will be asked whether you give your consent for your child to take part. If you do agree you will be asked to sign a form giving your informed consent. The treatment team will not put pressure on you to agree, and your child will receive the best treatment available whatever you decide.

- Deciding on whether to take part in a trial can add to the stress of coping with a sick child and the bewildering range of processes associated with treatment. It may seem as though the treatment team is passing over to you responsibility for deciding what treatment your child should be given. In practice, however, the treatment team will only invite you to join a trial when it is considered in the best interests of your child, and where both your child and the advancement of neuroblastoma treatment are likely to benefit.

Randomisation

- If you agree to take part in a trial the decision about which of the treatments being tested will be given to your child may be decided by random allocation, or randomisation. This takes the decision out of the hands of the treatment team; ensures that there is no bias in who receives which treatment, and ensures that the results from the trial are valid and meaningful.

If you have access to the Internet you can find further information about clinical trials and how they are managed on the website of the Children's Cancer and Leukaemia Group (CCLG) at http://www.cclg.org.uk/treatmentandresearch/content.php?2id=17

- Because this is such a rapidly changing field, it is not possible to give details about any particular procedures now being tested, but you may be reassured that your child will never be subjected to any test, procedure or 'new' drug without your full knowledge and permission.

Beginning Treatment

- If your child starts upon the treatment regimen recommended, you may have to stay at the main Oncology centre during the early stages of treatment (one or two cycles of chemotherapy). This will depend on the current treatment protocol used.

- After the early stages of treatment, it may be possible for you to have some of the treatment at your local hospital thus causing less disruption to your family life. This will depend on whether it has a Paediatric Unit that is equipped to supervise the giving of your child's therapy. This can be worked out with you according to your preferences, but you will have to return to the main Oncology centre from time to time for any surgery or re-evaluation.

- When you take your child home after the initial diagnosis and first treatment, you may feel nervous and worried about coping without the back up of the hospital team. Your local Paediatrician and your doctor will have been put in the picture, as will the nurses and social workers you met in the hospital. Your community oncology nurse and maybe the local community nurse can provide a link between the hospital and your home.

- In most centres, there will be a 'home liaison team', or a team known by some similar name, which provides a link between the home, the main treatment centre and the local health care team. You can be reassured that you are welcome to telephone the hospital at any time of the day or night if you are concerned, as a doctor who knows your child will always be available or 'on-call'.

- Perhaps it would be helpful in Part Two of this booklet to consider in more detail how you may be able to help your child through the tests and treatment to come, and how you and your family may feel as you try to return to your normal way of life.

Part Two
Telling Your Child

- What to tell your child about their illness and treatment and how to discuss their fears and worries is a puzzle for most parents. A parent's natural reaction is to want to protect their child from knowing about their illness, mainly because the adult finds the word 'cancer' frightening. Many parents feel that their child is too young to understand what the diagnosis means.

- A child of any age will either be puzzled or frightened by what is happening. Children quickly notice a tense atmosphere, or overhear conversations, and they may become worried about what they are not being told. An explanation appropriate to your child's age is vital.

- You are the most stable, trustworthy, familiar people in your child's world. Throughout the difficult experience to come, they need to trust that you will provide the security they have always felt. Your child will know from other peoples' reactions that something very sad and frightening is going on and they will see other children in the ward looking similar and having the same type of treatment.

- At any age, if your child feels they cannot trust you to listen to their worries and answer questions honestly, insecurity will result. A child's way of expressing this may be through anger and aggression, or by behaving like a much younger child. Even a very young child can become depressed and withdrawn. Of course, it is easier said than done to be open with your child about such a difficult subject, when you, too, may find it hard to accept.

- It may help to talk over with the hospital staff the kind of questions your child may ask and the answers that seem to help children of your child's age. Alternatively, you may like the doctor to have a chat with your child with you present, having decided with you first what they will say.

- A very small child needs only to know why their mother and father seem to be letting doctors and nurses do unpleasant things to them. One way to do this is to link the explanation to the symptoms they are experiencing. Cancer is a concept totally beyond a toddler, so a simple truthful statement is all that is needed.

- As an example, it may be possible to say something like "*... The pain in your tummy is because there is a lump there which the doctors found by taking special pictures. You must take the medicine to try and make the lump go away and that will make your tummy ache better .....*" Your child may not understand why they have to have the drip or injections, so you could perhaps explain that "….*The medicine has to be given by 'needle' or through the 'tube' because it is very strong and it might hurt your mouth if you swallow it...* ".

- A small child will have the greatest comfort from you being with them and comforting them and will not be too worried about treatment details so long as they are secure in your support.

- A slightly older child may be able to understand more about what cancer is. For example, they may be able to understand that tumour cells can break off from the main lump and go to other parts of the body.

- A school age child may have heard the word 'cancer'. Many parents fear that for their child to know they have a cancer will be frightening, and want to prevent their child from hearing the word. However, they will certainly pick up ideas from conversations with other children. Their lack of hair, for example, may cause another child to recognise the diagnosis and mention the word 'cancer'. Therefore, it will be impossible to hide the truth about the diagnosis.

- It is better that your child learns about their own disease at the beginning from trusted parents rather than hearing things from others that may frighten and worry them. They should know that

they have a special form of cancer which only children get and that the doctors have very strong medicine to give them to try and get rid of it.

- An older boy or girl, perhaps pre-adolescent at the upper end of the neuroblastoma age group, will have a much more adult concept of cancer.

- Whilst it is often very hard for parents to be entirely truthful, an older child will usually be very disturbed by hiding the truth or not telling the full facts. Whilst there is no need to go into enormous detail at the outset, they will need to understand the disease in the proper terms and be given a truthful outline of the treatment plan.

- The older child may also need to talk about worries such as their appearance, schoolwork, ability to keep up with their peers, etc. Members of the treatment team, such as the doctor, social worker or psychologist can talk to your child if you wish, or discuss with you the kind of things you can say to answer their questions.

- Just like a younger child, they will need your presence and support very much, but may also need to keep some of their independence by talking and sharing worries, in private occasionally, perhaps with other members of hospital staff or a peer group.

Coping with Tests

- Whatever your child's age, a truthful approach to what is happening is also needed when helping to prepare them for tests and investigations. It is very tempting to try to calm frightened toddler by the reassurance that "...*it won't hurt...*". If this is not true, your child may lose trust in you and feel very insecure. Better, if you can, to find something positive in a nasty situation. You may say, for example, "*... Yes, this finger prick will hurt a bit just for a moment, but mummy will stay with you all the time and then we'll go to the playroom/make a drink/read a story ... etc"*.

- Asking your child to be a "*big girl*" or a "*brave boy*" are usually useless when the child is frightened. Approaches such as "*We will all shout 'ouch' together when the prick happens*", can help the child to know that the adults appreciate that it hurts a bit and it isn't shameful or babyish to cry.

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

You and Your Family

- When you have been in hospital a few days, and the routine is becoming a little more familiar, you may begin to think about how you are feeling, how you are coping with the situation, and what it all means for you, your family and your lifestyle. Your first feelings on being told that your child has cancer were probably those of any person who has received a terrible shock: disbelief, fear, numbness, misery and perhaps anger.

- It is difficult to hear or take in what is being said, and many parents describe a sensation as if they are in a dream from which they hope to wake at any moment. You can feel physically ill from shock or worry and some people's misery expresses itself in anger "*...Why should this happen to me? ....* " or "*...Why is this happening to us, we have done nothing to deserve it?...*" It is certainly a deep-rooted feeling that such a catastrophe must be a punishment for something.

- The cause of neuroblastoma remains unknown. This means that nothing that you did or did not do as a parent had any effect on the disease. No particular food, habit, environment, smack, bump or previous illness can be said to have caused the neuroblastoma. Doctors are as certain as they can be that it is not an inherited condition, i.e. it did not come from one or other side of the family. It may be that another member of your wider family has had or has got a cancer, but there is no known link with neuroblastoma.

- It may help you to remember that all forms of adult cancer are very different from neuroblastoma. Whilst some forms of adult cancer are undoubtedly linked with environmental causes e.g. smoking, such things do not seem to be the cause of neuroblastoma. Furthermore, there is no evidence to suggest that any event during the mother's pregnancy is linked with neuroblastoma.

- The incidence of neuroblastoma seems more or less stable over the period where accurate records exist. Also, the frequency

of this cancer is roughly the same throughout the world. It means that a certain number of children each year will develop neuroblastoma and these numbers remain fairly constant for children across the world from all races and environments. However, the need to blame someone or something for the tumour is very great, and all the logic in the world is hard to accept when the cause of the disease remains unknown.

- Some parents want to blame the doctors for not detecting the cancer in time, whilst others blame themselves or feel that they should have been more concerned when their child was first off colour. Unfortunately, it is probably the case that most neuroblastomas have already spread in the child's body by the time any symptoms are noticeable. Therefore, the treatment or the outlook would probably not be very much affected by the time of diagnosis. It may be helpful at this stage to talk over the way you feel with others in the hospital. The medical and ward nursing staff understand that your reaction is one of shock, and a social worker, community nurse or psychologist will have the time to listen and discuss with you what has happened and the way you feel. They can also help you to organise yourself at this stage when you may not feel able to make practical decisions or plans.

- If you are at a treatment centre a long way from home, it is understood that you and your child need the support of your spouse, partner, some other relative or a friend. Help can be given with accommodation in or near the hospital; money can be given to either help with visiting or cover expenses such as long-distance telephone calls, etc.

- It is a good idea to have someone with you right at the beginning to hear what the doctors have to say about your child's disease and treatment. This means that you have someone to talk to later, which may help you to understand what has been said. It also means you can share the stress of telling everyone else what is happening.

- Your own or your spouse/partner's reaction may be bewildering and upsetting to you both at first. It helps if you can discuss with one another the way you are feeling and what is worrying you. Neither of you should bottle up your feelings for fear of upsetting the other. Undoubtedly, you are both distraught and trying to hide your feelings from one another is an extra strain. Many people, particularly men, feel that crying is something to be ashamed of. Fathers, however, do cry just as often as mothers when hearing about their child's disease and it is not a sign of 'cracking-up' or not being able to cope. It is a natural reaction and a necessary release.

- Most parents feel they do not want to show their distress in front of their child, but sometimes you may not be able to hide your feelings and young children will not usually be too alarmed if a simple explanation is given "*...Mummy/Daddy is feeling upset because you are poorly...*" or "*...because you have to be in hospital at the moment...*".

- Telling relatives and friends can be very taxing. At a time when you are trying to come to terms with what you have heard, it is a strain to have to repeat it, perhaps many times, in response to telephone calls from very well meaning and worried relatives.

- The presence of one or two understanding relatives and friends may be a great comfort and support, but sometimes parents and patients can feel overwhelmed by a stream of visitors or calls. Some parents have found it helpful to have a family member on 'telephone duty' at home who will give any news to other relatives after daily contact with the hospital.

- Close family members, like grandparents, may also find it helpful to talk with the doctors so that all who are closely concerned with your child have the same information and understanding of the disease and proposed treatment.

Brothers and Sisters

- Brothers and sisters need to see their sick brother or sister and to understand what is happening. Many parents feel that it will be frightening for their other children to see the sick child in hospital. However, children's fantasies of what may be happening to their brother or sister are often more worrying than the reality. Brothers and sisters are usually reassured by seeing for themselves where and how their sibling is. It will also help you to explain to brothers and sisters what is happening to the sick child if they have seen the hospital surroundings and any treatment apparatus. Ask the ward nurses about bringing them to the ward and about any special precautions that may have to be taken, such as wearing a special gown. This may need explaining to the visiting child(ren) before they come.

- Depending upon age, and despite the most careful explanations, brothers and sisters may still, naturally, be a bit wary at first about what is happening. They may see that the child has changed, is perhaps more frail and thinner, has maybe lost hair and is not able to play with them and join in the activities that they have usually enjoyed together. They may also have been told that they have to be extra careful or good when their brother/sister comes home because they are poorly.

- Brothers and sisters need an explanation about neuroblastoma appropriate to their age. This can be similar to the one given to your sick child. Alternatively, your child may be old enough to explain about their illness and treatment for themself.

- Your child's brothers and sisters may worry that what has happened may also happen to them. They will need your reassurance that they are not likely to develop cancer. They may also need to know that it will not happen to you or their other parent.

- Children may also feel guilty about their brother’s or sister's illness. They may feel that it is all somehow their fault, perhaps

because at some stage they have been jealous and have wished something horrible would happen to the child who is now sick.

- They may be jealous of the sick child even though you may have prepared them carefully about the illness and its treatment. The sick child has, after all, gained all your attention and may, perhaps, have received toys and presents from the family and neighbours. Once home from hospital they may be seen to be 'getting away' with things more than before.

- It is very hard for you when you are tired and worried yourself to have to give extra reassurance to your other children. However, to do so may prevent some of the problems of jealousy. Try very hard not to favour your sick child and, perhaps, see if you can find at least a little time each day when you can give your undivided attention to your other children; either by a reassuring phone call from hospital, or some special routine when you are back home.

Going Home

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

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

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

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

1. Behaviour

The question of discipline is a very thorny one. Many parents say that they cannot imagine ever being able to scold or punish their sick child again and it is very tempting to overindulge them. However, your child needs more than ever to be reminded of the secure boundaries their parents have always set for them. If they are suddenly allowed to 'get away with murder' it will not be reassuring to them that life has returned to normal and it will not help to reintegrate them with their brothers, sisters and friends. Even in hospital or on out-patient visits, where changes in

behaviour may be expected due to stress, extreme rudeness or aggression need not be tolerated. Extreme behaviour on these occasions is often, in any case, the result of fear and insecurity. It may be that your child would be helped, as mentioned earlier, by a simple truthful explanation and reassurance. They also need to know that they can still rely on their parents to offer boundaries and control over a world that to them seems to have become frightening and insecure.

- It is not a good idea to indulge your child with piles of presents on their return home or to have promised them expensive and extravagant gifts. If visitors who do bring gifts for the sick child can be persuaded to include a gift for brothers and sisters, so much the better. It is unwise, and unfair, to lead the child to expect gifts on every hospital admission (as there may be many) or to offer gifts as 'bribes' for undergoing medical procedures or treatments.

2. Sleeping

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

- Needless to say, allowing the sick child special treatment, such as sleeping with you in your bed, would probably create jealousy and difficulty later with brothers and sisters.

3. Eating

You will know that in the case of neuroblastoma there are no particular restrictions on diet and no set medicine to take between

hospital treatments. Some parents have found, to their great encouragement, that as treatment progresses the child does regain energy and appetite between or after each course of chemotherapy.

- Eating is often an issue that causes concern to many parents. Almost inevitably your child has lost weight, firstly because of the neuroblastoma itself and then because of the drugs that may have caused sickness and loss of appetite. Some children do not regain their former appetite or weight until the whole course of drug treatments has finished. It is very natural to want to 'build-up' your child and preparing nourishing food is something very positive that you can do to help them through the experience of their illness and treatment. However, it can be very disheartening if your efforts are then refused, and worse still, if every meal becomes a grim battle between you and your child to get them to take a couple of spoonfuls.

- You can only try and offer your child whatever they fancy, and many parents find that their child's taste tends towards 'junk' food. This may not meet with your approval, but it is best not to be too rigid at this stage. You can always guide your child towards a more balanced diet as their appetite improves.

- If you have been in the habit of giving your child vitamins regularly, this will do no harm, nor will most 'tonics', but it is best to check with your doctor first.

- Unless your child's doctor is worried about excessive weight loss it will be considered fairly normal for your child's appetite to fluctuate and for them to remain rather thin throughout treatment. You may find it helpful to talk to the dietician at the hospital, who may be able to suggest ways of presenting nourishing and weight-building food.

- Sometimes, supplementary feeding through a tube from the nose to the stomach, or even TPN (total parenteral nutrition) through the central line, is needed.

Getting Back to Normal

- It is very tempting to become overprotective of your sick child and perhaps of your healthy ones too in view of what has happened. You have probably been told by the treatment team to allow your child to do whatever they feel able, and it is very good to encourage them to regain their old skills and confidence as they feel better. This may be merely playing outside with friends or, for an older child, going back to Cubs or Brownies again or joining in a school trip, etc.

- Much of your desire to protect your child may be the result of medical advice to keep them away from sources of infection. Many parents agonise about the extent to which their child should mix with other children. Obviously, you will follow the advice of your child's doctor, but on the whole they should enjoy the benefits of mixing with others, with sensible precautions of course.

- You will naturally not want to take your child along to playgroup or school if nearly every child there has a cold. However, having the neighbour's child visit, or taking your child with a friend to the park, should do no harm at all.

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

- Even if your sick child does come into contact with measles or chicken pox there is no need to panic, but you must let a doctor know immediately. It may be possible to give your child a special injection in case of chicken pox, (called 'ZIG' standing for zoster immune globulin) to either reduce the attack or to prevent it

completely. Some centres use an alternative drug called aciclovir instead of ZIG for this purpose. Zoster is the name of the chicken pox virus. It is identical to the virus causing 'shingles', which should also, therefore, be avoided. If you have a concern about possible contact, telephone the hospital or your doctor for advice.

- If you think your child has been in contact with someone with measles or chicken pox, do not bring them to the hospital and walk them through the ward or out-patients department in case this spreads infection to other children.

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

School

- Starting or returning either to school or nursery is another hurdle for your child after a diagnosis of neuroblastoma. As mentioned before, your child's need for normal contact with their friends and social group should be weighed against your very natural desire to protect them from infections, stress, over-tiredness or even teasing.

- You may not feel that a five year old is missing much schoolwork, or that even a ten year old's schoolwork is the most important of your concerns at present. However, to a child who already feels different and isolated from their friends, it is very important to keep up the normal activity and stimulation of school as far as possible. They will then cope better amongst their friends and can slip back into the school routine when they are able, without the added disadvantage of having fallen behind.

- Regular contact with school friends or nursery class mates can be very helpful while your child is unable to be at school, through visits, tapes, letters and photos. The hospital teacher, working with the school or nursery, can provide material for homework or activities as appropriate.

- If it is quite impossible to return to school for a while, the Local Education Authority will provide a home tutor and it is important to take advantage of this facility.

- Even if your child cannot manage full time schooling, perhaps they can go for some half days or even for some favourite lessons or special activities during the school week. To help your child's return to school, you must take the head teacher and class teacher into your confidence.

- Many schools will take a sympathetic and constructive approach to the particular problems of a child with cancer, but it is not surprising if they know nothing at first about neuroblastoma.

They will need your guidance as to your child's capabilities. They may also need to prepare classmates for your child's return by explaining about treatment and the reasons for hair loss, etc, and thus prevent teasing that is generally the result of either ignorance or fear. Once children know why one of their friends looks or behaves differently, they are often able to be protective and sympathetic.

- If your child is very young, you may need to explain to other parents and neighbours what is happening. It is hard for you to be the one to make the running at this time, but there are still some very silly myths and old wife's tales about cancer. From a combination of fear and ignorance, people may be either unable or embarrassed to approach you. A simple explanation and reassurance that your child's condition is not 'catching' will usually help people to become sympathetic and supportive.

Asking for Help

- Hopefully, you will have had the support of really close friends, but you may discover that some people are embarrassed or do not like to offer help for fear of 'interfering'. However, if asked, they are often delighted to be able to do something for you and your child.

- You should try not to feel too proud to ask for what help you can get to make your own life and family organisation simpler. If you need your other children taken to school or need a lift to the hospital or a bit of shopping, for example, then say so. If a neighbour asks "*...Is there anything I can do?*…." try not to cut yourself off from friends and neighbours but give them the chance to express their care and concern for you and your child.

- You will probably get to know your doctor quite well, as well as your local health visitor and social worker. All of these people can be helpful to you and can put you in touch with the services you need, so do not hesitate to ask for help. Your social worker, in particular, can become a friend with whom you can talk things over as well as address practical problems.

- These professionals may be in a position to offer you financial help or other assistance which can benefit your child and help ease the burden of caring for them. At the back of the booklet, on pages 53 to 55, there are addresses of helpful organisations that you may like to contact.

Time for Yourself

- Although much is said about leading a normal life, every parent will say that life can never be quite the same again. At the back of your mind is always the knowledge of your child's illness, and it is a struggle sometimes not to allow your family's whole life to focus on hospital visits, blood counts, clinic trips, etc. If you possibly can, you need to keep some privacy for yourself and your spouse/partner or special friends. This gives you some time of the day that is not devoted to caring for or thinking about your sick child.

- You need, if possible, to spend some time enjoying yourself. Because your child is sick, it is not wicked to think about a night out, to enjoy a film or spend an evening with friends. A break from your child may help you both to cope better at other times.

- Even when you are in hospital with your child, you should not feel guilty about going out for a drink or a meal, or even just for a break to get some fresh air. There is no reason why your child should not be left with a reliable relative or baby sitter during the times they feel all right. Keeping up family traditions, holidays and celebrations will be beneficial to all of you, including your sick child.

- Some parents fear that their marriage or relationship may come under strain because of the stress. It seems to be a common belief that there is an increased rate of marital breakdown in families where a child has cancer. What is likely is that previous relationship difficulties may be aggravated by the stress of the situation. On the other hand there are many husbands and wives who feel their partnership is strengthened by the need to share in the care of their sick child and the need they have of one another's support at this time. The main thing is to realise that each parent will cope in different ways and, as long as these ways are not harmful to self or others, try to accept that each is doing his or her best to support the child and to 'keep things going'.

Your own Feelings

- You would have to be superhuman if at times things did not get on top of you. This is probably the first time that, as a parent, you do not have full control over what is happening to your child.

- Although the treatment team will try to keep you well informed about your child's progress, this helpless feeling can be very frustrating and cause you to lose some self-confidence. There may be occasions when you feel so worried, depressed and tired that you wonder if you are 'breaking down' or even 'going mad'.

- Some parents describe either moments of panic or periods of having morbid thoughts or dreams, and almost all parents at some time think about the possibility of their child's death. Many parents admit to 'rehearsing' in their imagination details of the events either surrounding or following the child's death. Such thoughts frighten many parents into a kind of superstitious belief that by dwelling on such things they are somehow willing them to happen.

- These thoughts may come suddenly when the child is quite well, and parents fear that they are being wicked or unnatural in some way. They are not, of course. These imaginings are a way of 'facing up' to the worst that could happen and an attempt to come to grips with the possibility.

- It is very common for parents to feel that everywhere they turn they see something about cancer or about children suffering in some way. It is probably because such parents have become very sensitive to these topics that they find themselves becoming extremely distressed.

- These kinds of feelings, and many other thoughts and worries, can be eased a little by sharing them. If you worry that you are the only person thinking or feeling this way, you may want

to hide it from anyone else in case other people assume you are not 'coping'.

- If you can manage to confide in someone; your spouse or partner, another parent or one of your child's treatment team, you may be relieved and reassured to find that others have experienced similar feelings. These are a normal part of the process of adjusting to the news of your child's illness and the stresses of caring for them.

- To say that these feelings are quite common is not to belittle the distress they cause you, but to emphasise their 'normality'. Your child's treatment team know that many parents feel as you do. They understand that you may feel worried about almost any aspect of your child's illness and treatment.

- You may feel depressed or exhausted and need a listening ear for yourself when you are in hospital with your child. You may find it helpful to talk things over with one of the treatment team, perhaps the attached social worker or psychologist. No one will make judgements about your capabilities as a parent, or label your child as having special problems or difficulties. Every member of the team has their own area of experience and expertise, and they are there to share this with you and to help you, your child and your family in any way that they can.

- This sharing of experience is very important throughout and after your child's treatment. There is not the space to go into all the reactions, fears, worries, even joys and satisfactions that most parents feel and gain while caring for their child at home and in hospital.

- You know your child best, and the medical staff who have the responsibility for recommending and administering treatment need to share your knowledge and views of your family's and your child's personalities, preferences and any problems. Once they are familiar with these, they will be able to help with any problems that arise.

Coming off Treatment

- The months of treatment feel like a long and anxious time, and even the eventual relief of coming off treatment may be overshadowed by a continuing fear of the return of symptoms. Even though treatment may have been difficult, and hospital visits a strain and inconvenience, the drug therapy has probably provided a sort of insurance for parents. Many say they have a feeling that the disease has been wiped out or held firmly at bay while the drugs were being given.

- If your child, like many, has shown a rapid improvement, even a return to normal health, during the course of chemotherapy, it is not uncommon to think that stopping treatment is tempting providence. You may want to discuss with your doctors again why it is thought best to stop treatment after a certain time.

- Parents describe the 'coming off treatment' as a time when it feels that the 'safety net' has been removed and that they are entering a period of great uncertainty. Some parents who have kept up their spirits throughout treatment find, to their concern and surprise, that now is the time when they feel depressed. They may describe feelings similar to one father who said "*...My daughter is now perfectly well, cured it seems to me, but we have to wait five years for it to be confirmed; it is like living with a time bomb...*".

- The uncertainty can be eased a little by the regular follow-ups that your child receives. Clinic visits and examinations will perhaps cause you a worrying few days beforehand, but reassurance that everything is well will carry you through to the next visit.

- Your own instincts are probably as good as any ultrasound or blood test at telling you how your child is getting on. Your child's good appetite, mood and energy will be an indicator to you that things are going well. As time goes on, you will begin to feel a little less fraught and enjoy your child's good health day by day.

- If you are worried at any time, the same 'rules' apply as when your child was on treatment. You can always get in touch with the hospital and talk things over and arrange for your child to be examined. Your child, like any other, will still have their fair share of ordinary ailments and no-one will mind being able to reassure you that a temperature or tummy upset is just a passing bug.

- If return of the signs and symptoms of the neuroblastoma should happen, your distress and anxiety will be fully shared and appreciated. There is no fixed protocol of re-treatment that could be set out here, but the best treatment for your child would be fully discussed and individually planned.

- There are many drugs or procedures that could be suggested, and there are always treatments available to alleviate any symptoms or discomfort your child may experience. Every member of the team, who will no longer be strangers to you and your child, will continue to want to try and help with every aspect of your child's care.

The Future

- New approaches to cancer treatment are being researched and developed all the time. There is, as you know, no miracle drug or guaranteed cure as yet and it is doubtful if the eventual answer will be a simple single agent. Oncologists and researchers feel that the best hope lies in the refining of drugs and techniques that are known already to be effective against neuroblastoma.

- Very sophisticated techniques of treatment are now being developed which you may have heard about in the media, some of which are now coming into use at the treatment centres. You may be sure that these procedures will be discussed fully with you and will be available for your child if thought appropriate.

- Although caution and patience are so necessary before claiming a cure for any cancer, there is very real hope that present research will make progress towards the effective treatment of neuroblastoma.

Glossary

Abdomen	'Tummy'.
Anaesthetic (local Anaesthetic)	Drug(s) to put patient to sleep or to numb a particular area of the body.
Aspirate	To draw into a syringe.
Benign	Not cancerous. A tumour made of benign cells is less likely to spread.
Biopsy	A small piece of tissue taken from some part of the body in order to examine it under a microscope.
Blood Count	The number of cells of different types contained in a blood sample.
Bone Marrow	The substance (at the centre of the large bones in the body) which 'manufactures' blood cells.
Central Line	A tube inserted under the skin into a large vein to make the giving of drugs and the taking of blood samples easier.
Chemotherapy	Drug treatment to kill cancerous cells.
CT Scan	A special test similar to an X-ray.
Diagnosis	The name and type of the patient's illness.
Ganglio -neuroblastoma	A special type of neuroblastoma made up of 'less aggressive' tumour cells.
Glomerular filtration rate (GRF)	A special test to see how the kidneys are working.
Hickman Catheter	See "**Central line**".

Informed Consent	Permission for a patient to take part in a medical trial, given after the benefits and risks of the trial have been fully explained.
Intravenous (IV)	Into a vein - for example as when drugs are given directly via a drip.
Lymphocyte	A special type of cell in the blood which fights infection.
Malignant	Liable to grow and spread - as in a malignant tumour.
Metastasis (pl. metastases)	Any subsequent tumours arising from tumour cells which have broken away from the main tumour.
mIBG Scan/ Treatment	Meta-iodobenzylguanidine (mIBG). A procedure involving radioisotopes for diagnostic or therapeutic purposes.
MRI Scan	Magnetic Resonance Imaging.
Neutrophils	One of the types of blood cells which helps to fight infections.
NMR Scan	Nuclear Magnetic Resonance.
Oncology	The study or specialisation of cancer treatment.
Oncologist	The doctor who specialises in cancer treatment.
Paediatrician	A doctor specialising in the conditions and diseases of children.
Platelet	A type of blood cell that helps blood to clot.
Port	A special form of "**Central line**".
Primary	The first or main tumour.

Prognosis	Outlook or anticipated outcome of a disease and its treatment.
Protocol	Treatment plan.
Radiology (Radiologist)	Specialisation of diagnostic X-ray techniques and interpretation of X-rays. (The doctor thus specialising)
Radiotherapy	Treatment with X-rays to kill tumour cells.
Randomisation	A method for allocating patients to medical trials to avoid bias.
Secondary	See "**Metastasis**".
Sedation	Drugs to make the patient relaxed and sleepy.
Toxic (Toxicity)	Poisonous (potential to poison or harm).
Trephine	The small piece of bone taken from the site of a bone marrow aspirate - for examination under a microscope.
Tumour	The lump formed by a collection of cells ('malignant' or 'benign').
Ultrasound	Examination by sonar whereby the body organs are outlined by sound waves onto a screen.
VMA patients	A substance secreted in the urine of who have neuroblastoma.

Helpful Addresses

- Some of these organisations are concerned with offering only financial help; some offer support and counselling as well as information. In addition your doctor's surgery or child health clinic may be able to advise you about facilities and benefits available locally.

Action for Sick Children, Unit 6, High Lane Business Court, Rear of 32 Buxton Road, High Lane, STOCKPORT, SK6 8BH
Tel: 01663 763 004 Freephone : 0800 0744519
Web: www.actionforsickchildren.org

- Supports sick children and their families, and works to ensure that health services are planned for them. It was originally a pressure group to improve the plight of children and their parents in paediatric wards. Now it has information leaflets, videos, etc., available about children in hospital.

ACT, Brunswick Court, Brunswick Square, Bristol, BS2 8PE
Telephone: 0117 916 6422 Helpline 0845 108 2201
Email:info@act.org.uk Web: www.act.org.uk

- ACT maintains a database of support services for parents with sick children, and can give information about the location and activities of community nursing teams (including "Diana Nurses").

MacMillan Cancer Support, 89 Albert Embankment, London SE1 7UQ. Freephone:0808 808 2020 (9 - 9 Mon to Fri)
Email: cancerline@macmillan.org.uk Web: www. Macmillan.org.uk

- This is a self-help organisation for patients and their families. Volunteer counsellors are often cancer patients themselves. CancerLink may be able to put parents in touch with other parents of child patients. There are meetings, local groups, and telephone contacts. MacMillan Cancer Relief may also offer financial help for costs incurred by illness and treatment. This is not limited to child patients.

Contact a Family, 209 - 211 City Road, London, EC1V 1JN. National Freephone: 0808 808 3555 (10 - 4 Weekdays)
Email:info@cafamily.org.uk Web: www.cafamily.org.uk

- This UK charity offers information, advice and support, and a linking service to families who have a child with a disability or special needs.

Department for Work and Pensions. Telephone 020 7712 2171
Web: www.dwp.gov.uk

- Information leaflets and application forms for state benefits or grants and information about eligibility for these are normally available from your local DWP Office or at the above website.

The Family Fund, Unit 4, Alpha Court, Monks Cross Drive, Huntington, York YO32 9WN. Telephone 0845 130 4542
Email: info@familyfund.org.uk Web: www. familyfund.org.uk

- This charity aims to ease the stress of families in the UK who care for handicapped or sick children, by providing grants and information related to the care of the child. It is funded by central government.

Gingerbread / One Parent Families, 255 Kentish Town Road, London NW5 2LX . Freephone: 0800 018 5026 (9am - 5pm M - F)
Web: www.oneparentfamilies.org.uk

- Support organisation for all lone parents and their children.

Helen House Children's Hospice, Helen & Douglas House, 14A Magdalen Road, Oxford, Oxfordshire, OX4 1RW
Telephone: (01865) 794749. Web:www. helenanddouglas.org.uk

- This was the world's first hospice for children, and now offers 'respite', advice and support for parents caring for a sick child in the UK.

The Neuroblastoma Society, 2 Caesar Court, Moss Street, York, YO23 1DD Helpline 020 8940 4353

Web:www.neuroblastoma.org.uk

- The twin objects of this registered national charity are to raise funds for UK medical research into improving the treatment of neuroblastoma, and to offer support to parents with a neuroblastoma child. The Society can arrange for parents of a newly diagnosed child to link with one of its members to share experiences.

CLIC Sargent Cancer Care for Children, Griffin House, 161 Hammersmith Road, London, W6 8SG.
Freephone: 0800 197 0068 (M - F 9 - 5)

Email: helpline@clicsargent.org.uk Web: www.clicsargent.org.uk

- Financial help with any expenses directly incurred because of the child's illness and treatment. The social worker at your child's treatment centre may be a Sargent social worker.

- As well as the above organisations your local Social Services Department or Occupational Therapy Department are other useful contacts for advice about facilities and benefits available to you locally. Help may be available through such diverse services as childminding or baby sitting, hospital car or volunteer driver service or loans of special aids, equipment or buggies, etc.

- A toy library may be available to you locally and may have, or be able to obtain, any special toys or play equipment which your child would enjoy but which would be too expensive or of too short-lived an interest for you to buy yourself. Your library, Yellow Pages or Citizen's Advice Bureau or any of the above public services can also advise on such organisations as play groups, mother and toddler clubs, etc.

- If you need help to nurse and care for your child at home, such help is available from a community paediatric nurse. Talk to your doctor or health visitor about contacting a nurse in your own

area, or if the treatment centre has a 'home liaison team', they will help you to link up with support in the community.

- If you do not need actual nursing help at home, but your child would benefit from physiotherapy or speech therapy, do discuss this with your child's treatment team. These services can be given by home therapists and may be arranged through your treatment centre or your doctor.

- Finally, if you need help to cope with running a home, nursing a sick child and the many demands of the rest of the family, it may be possible to organise help at home with practical tasks or services to give you an occasional break, or while you stay in hospital with your child. Your local Social Services Department will advise you about these kinds of services, or the Sargent social worker at the treatment centre may be able to help. Don't hesitate to ask.

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