



End Of Treatment

What Happens Next?

A guide for parents





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From 1st August 2006 the UK Children's Cancer Study Group and UK Childhood Leukaemia Working Party merged to form the Children's Cancer and Leukaemia Group (CCLG)

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The end of treatment is likely to be a time of mixed emotions. This is probably the moment you have waited for since hearing the diagnosis. This can be a very unsettling time and you may be surprised you are not feeling the joy you thought you would. We hope this booklet will help answer some questions you may have at this time and help support you through the readjustment back to life without treatment. We have included some practical questions such as how often your child will be seen, as well as how you may be feeling emotionally when your child finishes treatment.

“ I thought that we would want to celebrate at the end of treatment, but we didn’t. It didn’t feel like the end, it felt like the beginning of the scary phase.”

PRACTICAL ISSUES

What happens at the end of treatment?

When your child first finishes treatment they will be seen frequently in the clinic. The frequency may vary between treatment centres, but is usually every 4-6 weeks, during the first year. At the very beginning you may still be seen every 1-2 weeks. As time goes by the interval between visits lengthens usually to every three months in the second year, until by the time five years have passed you may only need to be seen once a year. Your child will probably continue to be seen in a follow up clinic for many years after all the treatment has finished. They will still see the same team of doctors and nurses they knew during treatment. Sometimes follow up clinics are held on different days and times to the treatment clinics. If your child had treatment at a Shared Care centre you may still go there for some follow up visits.

When can the line/port come out?

As soon as possible after treatment is finished and any scans or tests are completed. Some children being treated for leukaemia or lymphoma may have their lines removed before treatment

finishes. The line or port will be removed under a general anaesthetic so it will mean coming to hospital as a day case. It may also mean waiting for a place on an operating list. This is because having a line out is always less urgent than having a line inserted.

“A nurse was very helpful and consoling when our son had his line removed, which provoked a flood of emotion from his mother.”

What happens if a blood test is needed when the line is out?

No one likes blood tests but unfortunately they may still be necessary and once the line is out this will either be with a thumb prick or using a needle. Some children are understandably upset at the thought of this. If it becomes a problem a play specialist may be able to offer help and support to cope with the blood test.

What happens at follow up visits?

The main purpose is to have a general check up with the doctor and arrange any tests that are needed. Blood counts are checked until they are back to normal. If your child had leukaemia, blood



“Having an anaesthetist talk about how our son’s last operation (to remove the line) went was very positive, as it was a happy conversation, marking the end of our journey of treatment.”

counts may be checked for longer. Any X-rays or scans are arranged.

Initially these tests are to check that there are no signs of the cancer/leukaemia coming back. The frequency of scans, including heart scans, X-rays and other investigations depends on the treatment your child has had. Your doctor will explain this in more detail. Many children will have no long term problems. As time passes the check ups increasingly focus on making sure that any long term side effects of the treatment are found and, if necessary, treated. The chances of the disease returning become smaller and smaller as time passes.

Your child will be weighed and measured at each visit, as it is important to check they are growing normally.

Will more immunisations be needed?

Yes, most children will need to have their baby immunisations repeated six months after finishing treatment. This is especially important if they had high dose therapy or a bone marrow transplant (see page 20).

What do I do if my child has a temperature/is unwell?

To begin with, it will be very difficult not

to worry every time your child is unwell, even though the most likely cause is a normal childhood illness. All children get ill. For parents whose children have never been seriously ill, it is easy to keep childhood illnesses in perspective; this is much harder if your child has had cancer. Every sore throat or headache may be a real source of worry to you.

From a practical point of view, in the first few weeks after treatment stops, your child may still be neutropaenic, or still have a central line and will need to come to hospital if they have signs of infection. However, once your child has a normal blood count and no line or port, it is usually best to see the GP first. They can decide if you need to go to the hospital. Your child's immunity will be low for up to six months after treatment. If they previously needed to take extra medicines when they came into contact with chicken pox or measles, they will still need these during this time - see section on school (page 22).

What should I look out for?

Parents often ask this and it is a very hard question to answer. Most children will finish treatment and rapidly be back to



“Talking to people in the same position makes you feel you are not alone and it makes you feel a lot better about everything.”

how they were. The follow up visits and tests are there to look for any problems. Here are a few things to be aware of:

- Many bruises at the same time that couldn't have been caused by normal activity (all children get some bruising).
- Repeated headaches/vomiting that are worse first thing in the morning.
- Lumps when your child is otherwise well. Small lumps in the neck, called lymph nodes, are very common in children when they have a viral illness, such as a cold or sore throat.

Most people are anxious after treatment stops and look out for things. If you are worried about any symptoms your child has, do contact someone at your treatment centre (see below).

Who can I contact if I am worried?

If you want to talk to someone in-between visits to the follow up clinic, you can usually talk to the Macmillan/CLIC Sargent or other specialist nurse who you had contact with during treatment. They can advise you or arrange for someone else to contact you. Alternatively you can contact the ward or clinic where your child was treated.

Is there anything my child can't do?

A few children are left with disabilities and may not be able to do all they could before, but generally we would encourage your child to return to all normal activities, as soon as they feel able. Some children feel very tired after certain treatments but the majority will recover within a few months of finishing treatment.

Why does my child feel tired?

When children first finish treatment they often feel tired because they are not as strong as before, they may have lost weight and they are not used to joining in all their usual activities. It takes time to build up their stamina. This is helped by eating a good balanced diet and introducing activities gradually. Each child is different but hopefully all children are soon able to attend school full time and join in sport both in and out of school.

If your child has been left with a new disability, returning to life as before can be very difficult. Hopefully your child's school will be able to help with their return and help them to join in as many activities as possible.

What about puberty and fertility?

Following treatment most children go into puberty quite normally and your child will be examined regularly at follow up visits to check this. Your child's fertility will depend on the treatment they received. This will have been discussed when your child was diagnosed. It is often very hard to remember everything that was said at the beginning so it is best to ask the doctor again if you can't remember.

At the beginning of treatment you will have been given a booklet called 'A Parents' Guide to Children's Cancers' (see useful publications - page 30). This booklet has a section on puberty, fertility and other possible long term problems.

Is follow up for ever?

This depends on the treatment your child had. The reason follow up goes on for many years and may be for ever is because of the possible long term effects of the treatment, not because of the possibility of relapse. It may be necessary to have heart scans or occasional blood tests. Follow up often carries over into adulthood – see section on transition (page 28).

FEELINGS/EMOTIONS



Is it normal to have mixed emotions?

Most parents whose children are approaching the end of treatment feel at least a little relieved that the time has come when their child's body can be allowed to recover from treatment. The chemotherapy drugs or radiotherapy treatments will stop and the family can start to look forward to planning life around holidays and birthdays rather than around chemotherapy schedules and hospital visits.

But for many parents this relief goes together with other feelings. Families are often exhausted after months of treatment. Parents sometimes feel they swap the worry about side effects for fears about relapse. At last parents have time to themselves, but that time may become filled with thoughts of what the family has been through and what the future might hold.

Why might I be thinking about the past/diagnosis?

The diagnosis of a child with cancer is one of the greatest traumas that a family can experience. When told of their child's illness, many parents are in a state of shock. They often feel that they are in

“Other problems, put on hold during the illness, now crowd in to be sorted.”

some sort of dream and that what is happening isn't real. At the time parents are told the diagnosis, there are very many demands on their thoughts and time. Most parents are also having to manage many other challenges "What will I do about work?" "How can I break this news to my child?" "There's nothing in the fridge"the list is endless.

During treatment, many parents do not have the time to really think through the diagnosis. It is when treatment slows down, that families can start to take stock of what has happened. For some families this involves going back through all the events around the diagnosis and the difficult times experienced during treatment. This, of course, can be a distressing process but is for some parents an important way to make sense of what has happened.

Why don't I feel like celebrating?

Parents often find that friends and families are overjoyed that their child has reached the end of treatment. They are greeted with big smiles and told how well the child looks. "Isn't it great that he's finished his chemo?" Yet most parents find that their own reactions are much more cautious.

"I felt very low at the end of treatment, when other people presumed I would be happy. I spent lots of time worrying about illness and trivial things in everyday life seemed to get out of proportion."



Many parents say that they cannot allow themselves to feel joy at having reached the end of treatment. How can they celebrate when there is a chance, however large or small, of relapse? The section below talks about coping with these fears.

For other families a celebration feels very appropriate. Your child and family have just got through the huge challenge of treatment. That in itself is a great achievement. The celebration might be nothing more than pouring unused medicines down the toilet or going to the park on what would previously have been a clinic day. Some families choose to have a family party or celebration at school. Others find that planning a holiday or some other enjoyable event gives them something positive to focus on. Whatever you and your child choose will be right, providing it feels right to you.

Dealing with fears of the cancer coming back

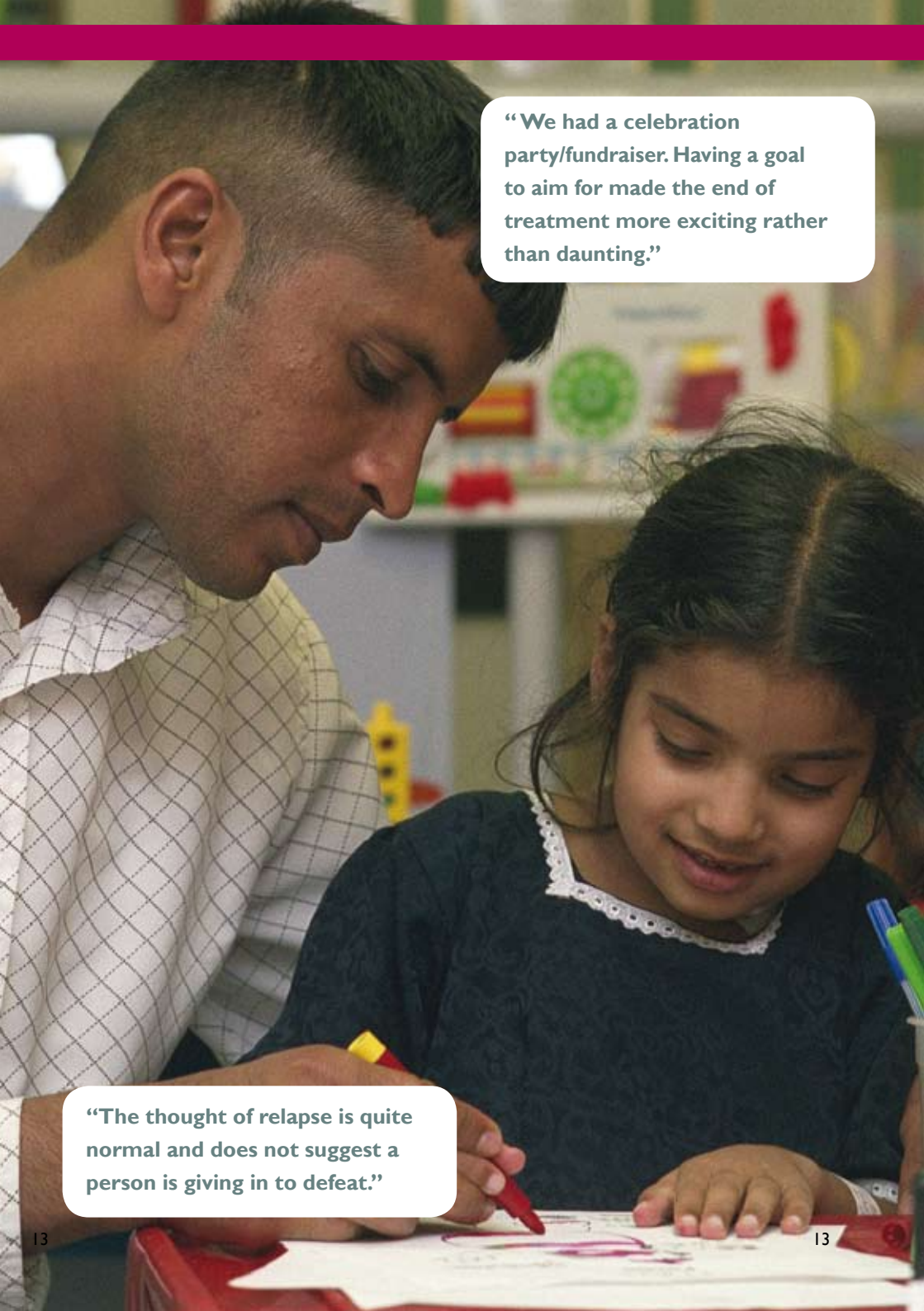
Parents often tell us that the end of treatment feels like the removal of the child's safety net. While the treatment is being given, families feel that everything possible is being done to beat the disease. No-one can tell you that

the disease will not return. Parents sometimes feel that they would prefer their child to remain on low dose chemotherapy for life, if it could guarantee that the disease would not return.

It is important to remember that your child's treatment was very carefully designed. Most childhood cancer treatments have been changed regularly over the last 30 years. Each change is the result of research that has shown how cure rates could be improved or side effects reduced. Your child has received a very carefully calculated amount of treatment. There is no evidence that any more treatment will help.

Some parents are able to put thoughts of relapse to the back of their minds, deciding not to think about this, unless it occurs. Others find that thoughts of relapse are never far away. If you are struggling with fears about relapse, it can be helpful to remember that:

- **Most childhood cancers never recur**
- The chances of relapse get smaller the longer your child has been off treatment.
- For many children there is still hope of a cure even if the disease does return.



“We had a celebration party/fundraiser. Having a goal to aim for made the end of treatment more exciting rather than daunting.”

“The thought of relapse is quite normal and does not suggest a person is giving in to defeat.”



“His treatment finished suddenly, before expected as his body couldn’t tolerate any more chemo. It was a strange feeling of elation and desertion.”

Where did everybody go?

During active treatment, families are regularly seeing professionals and other parents at the hospital.

Professionals can reassure parents that their experiences are not unusual. Other parents are in the unique position of really knowing how it feels to go through treatment with their child.

Yet suddenly at the end of treatment, fewer hospital visits mean that parents get much less access to these sources of support, just at a time that they may need that support the most.

Parents sometimes find that even people who seemed to have understood what the family was going through during treatment, now become less available and act as if life is now back to normal. It can be particularly hard at this time to find people who realise the pressures and fears that you still feel. With a little explanation, or perhaps by lending them this booklet, friends and relatives can be helped to appreciate the fact that you still have concerns and what some of these may be.

“I felt quite low and really missed reassurance.”

Sources of support

Some people find the end of treatment a positive time when they need much less support. But for others it is very important to have people who understand that their fears are continuing, although treatment is not. Try to find people who will let you be very open and honest about how you are feeling. Talking can help to make your own thoughts clearer. Some parents find that it is helpful to have some time to themselves.

You may find that some of these people can be helpful:

Friends/family members

Whilst your child is on treatment it is sometimes hard to maintain all your friendships. At the end of treatment the friends that have remained will hopefully continue to support you.

“Family helped by being able to talk to them and parents helped telling us to have some time to ourselves.”

“Friends took me out to lunch and health spa!”

Professionals from your treatment centre

The staff you met during treatment

will be aware of the difficulties parents and young people face at the end of treatment. Do let them know if you feel you need some extra support at this time.

Support groups and counsellors

Some treatment centres have parent support groups. These groups will usually be able to put you in touch with other parents who are in a similar position. Where these are not available there may be more general cancer or carer support groups in your area. Details of these are available from organisations such as Cancerbackup or Macmillan Cancer Support (see contact details at back of booklet).

The organisations listed at the back of this booklet will also be able to guide you to what counselling services are available in your area. Your GP may also be able to provide support and advice.

Coping with coming back to the hospital

Coming back to the hospital for check ups can be stressful. Some parents say that they feel increasingly anxious as the day of the appointment gets closer. Similarly, many parents feel much more relaxed afterwards and are able to

forget about the disease for a period. It is good to remember that the chances of a relapse being found at any follow up appointment are very small, especially if your child is well.

Your child may not understand why they need to come back to hospital. The booklet “What’s the point of coming to clinic?” may be helpful. Coming back to the hospital brings other stresses too. It can be hard to see other children who are still receiving treatment. For many parents this brings back difficult memories of their own child’s treatment. Returning to the hospital can also mean that parents hear news of children that they knew during treatment. If this news is bad, parents can become very fearful about their own child. It is always important to remember that even when children have the same diagnosis, each child’s illness is unique. Do ask to speak to someone about your concerns if you feel this would be helpful.

Coping with special occasions

Anniversaries of the time of diagnosis or finishing treatment can make whatever emotions you feel more intense, and for many that’s a mixture of sadness and joy.

In time many parents find that they can reach a balance between being grateful that their child is free from cancer and the sadness over the inevitable losses that the experience has brought. Some families will have many such losses to come to terms with, particularly where children have been damaged by tumours in the brain or by intensive treatments.

“We have moved into a new version of normal that certainly isn’t the same as before, but it’s a lovely place to be. It’s sweeter, if shakier and has a much better perspective on what’s important and what the heck isn’t.”

Talking to your child about the illness

As your child grows up the amount of information they need about their illness and its treatment increases. Many children will have been too young to remember much about the treatment period. It can then be tempting to try to protect them from the anxiety you feel by not telling them about their illness. Children are usually more aware than adults realise. Many children will learn about their illness from comments from

older siblings, cousins or friends. Finding out about the illness in this way can mean they only have part of the story and this may leave them with worries.

It may be hard for them to ask you if you haven't mentioned it. By talking openly to your child you are inviting them to share their thoughts about the illness openly too. This will give you a chance to correct any misunderstandings and give your child reassurance.

It is also important that your child knows about their illness so that they understand why they still need to come to clinic for appointments even when they are well. The section on transition at the end of this booklet explains more about this.

Brothers and sisters

Brothers and sisters of a sick child, like their parents, may continue to have worries about the sick child's health for some time after treatment. Many children will also realise that, even though treatment is over, parents are still focusing more on the child who has been ill. Brothers and sisters often need reassurance that they are loved equally



“We lived in a sort of bubble. The return to normality takes a long time.”



and that there are no longer any signs of the cancer. As brothers and sisters get older they are likely to need more detailed explanations about the illness, and perhaps reassurance that the illness doesn't run in families.

Getting back to a new normal

Life will of course never return to exactly how it was before your child was ill. However most parents feel that, in time, the family reaches a “new normal”.

For children this involves returning to nursery or school and as much as possible to a full range of leisure activities. Parents will also want to get back to normal activities, be that at work or home. For some parents returning to work can feel like a huge hurdle. If you have not seen colleagues since before your child was ill, coping with their reactions, however kind, can be a challenge. Some parents have found it helpful to visit their work place or meet up with colleagues before their first official working day, to help them to cope with their own and others' reactions in advance.

A new “normal” will also involve a return to usual discipline within the family. When a child is ill it is easy to let family rules be forgotten. However by insisting on good behaviour, parents can give a very positive message to both the child who was sick and their brothers and sisters:

“Yes Thomas was poorly, but he’s better now and we expect you all to be polite.”

It can be very encouraging to plan a holiday at this stage. If you want to travel abroad, you will need to seek advice about insurance (*see contacts at back of booklet*).

“Be realistic about the difficulties of readjusting back to “normal” life.”





If your child has had a Bone Marrow Transplant

The contents of this booklet will hopefully be helpful to you whatever form of childhood cancer your child has been treated for. However, for children who have had a bone marrow transplant, some aspects of their recovery will be different.

Following a bone marrow transplant, it can take a longer period of time for full immunity to return. This period is very individual and will depend on:

- The type of transplant your child has received (from a family member or unrelated donor).
- How quickly the new bone marrow starts working fully.
- Whether your child has had extra drugs to suppress their immunity and graft-versus-host disease.

Your child's doctors will be able to tell you when it is safe for your child to return to normal activities.

Children who have had total body irradiation as part of the preparation for their bone marrow transplant may also have some side effects that do not become evident until some time after treatment has finished.

Extra challenges if your child has had a brain or spinal tumour

For some children the damage done by the disease causes more problems than the treatment. Where a child's tumour has affected their physical activity, their mental abilities or personality, the end of treatment may not feel like an important milestone.

Of course parents of these children still have fears about relapse and the challenge of adjusting to a new normal life. However they also have to adjust to the limitations their child faces. For children who have had radiotherapy to their brain, it may be hard to know how treatment will have affected the child until several years later.

“I have huge worries about whether she will ever be able to live independently. And I've never talked to anyone about it, nor have they asked.”

Parents in this situation need extra emotional support and practical help to ensure their child enjoys life and achieves as much as possible. The organisations listed at the back of this booklet can give extra guidance if you are in this position.



PRACTICAL ISSUES AT SCHOOL



What about returning to school?

School plays an important role in helping a child maintain a normal routine and stay in touch with friends during and after treatment. Attending school gives structure to their day and a focus on the future. It's where children learn and develop communication and social skills and make friends. Hopefully, for most of you, your child will have already been attending school, but their attendance may have been interrupted, and your child may have spent days, weeks or even months away from school and friends.

Before your child goes back to school, the thought can be both exciting and worrying. It may also be very hard for you as a parent to 'let go' and allow your child to leave the safety of home. Your child may also be anxious, and feel as if they are 'starting all over again'.

Teachers may have already had contact with hospital staff during your child's treatment and further support can be given in helping your child return to school now they are at the end of treatment. It is important that information is given to the school relating to any medical issues still affecting your child. Your Macmillan/

CLIC Sargent or other specialist nurse can still be a link to the school if necessary.

Remember that most children feel strongly that they want to be treated as 'normal' in school, so informing the school and the child's school friends of this will help it to happen.

What happens if my child is in contact with chickenpox or shingles?

If, during treatment you were told that your child had enough of their own immunity against chickenpox then there is no need to take any action if contact is made.

If, when your child was on treatment you were advised to report any close contact with anyone with chickenpox or shingles, then this continues to apply for six months* following the completion of treatment.

After that time, if your child is in contact with anyone who has chickenpox or shingles there is no need for any action to be taken.

What happens if my child is in contact with measles?

For the first six months* off treatment, if your child is in close contact with a

**NB This period may be longer for children following bone marrow transplant. Please ask your own hospital doctor.*

confirmed case of measles, then you should report this to your hospital nurse or doctor so that appropriate action can be taken. After that there is no need to worry about any measles contact.

Can my child join in PE and swimming?

Yes. Your child should be encouraged to join in physical activity at school. Exercise is important for healthy living and unless there are any obvious reasons why your child cannot be physically active, a daily amount of exercise should be encouraged.

Once your child's central line has been removed and the wound has healed there is no restriction on swimming.

What about discipline/behaviour?

A child who has had cancer can be just as naughty as a healthy child, and there is usually no reason to treat them any differently.

After treatment, some children may take a little time to adjust and occasionally feel anxious or worried about school. They may become more tearful or express their frustrations in anti-social behaviour or temper tantrums. Try not to worry about this, most teachers will understand.

In time, by attending school regularly, your child will receive encouragement and support in adjusting to life at school.

Educational issues

Most children who have had cancer treatment will have no educational problems at all.

For some children, the cancer treatment may affect their intellectual development. One reason may be due to reduced energy levels experienced during treatment and their prolonged absences from school. In addition, some cancers may require treatment to control or prevent spread of the disease to the brain and/or spinal cord. This treatment can sometimes affect memory and learning abilities. Some parents and teachers report issues to do with lack of concentration. Informing teachers of the possible problems that may arise from this treatment means that where this is a possibility, children can be watched closely and given extra help if needed.

What increases the risk of educational problems?

The following can sometimes increase the risk of educational problems:

- A history of learning problems before the diagnosis of cancer
- Frequent or prolonged school absences
- Treatment that has affected hearing or vision
- Treatment that results in physical disabilities
- Treatment that includes the brain and spinal cord.

Children who have had treatment for a brain tumour are more likely to have received treatments that may affect learning and memory. The brain is a very complex structure that continues to grow and develop throughout childhood and adolescence. Some problems may not become noticeable until years after treatment is finished. Ensuring teachers are aware of this and carefully watching your child's progress at school will mean that extra support can be put in place if necessary. This extra help and support will help make sure your child reaches their full educational potential.

As your child moves further into the follow up period, it will be important for teachers to keep a close eye on their progress and to assess if any specific testing is required.

If you have any problems or need help and support when your child goes back to school, please ask your Macmillan/ CLIC Sargent or other specialist nurse, or another member of the hospital team.

“Children (with cancer) have had experiences and knowledge that most children of their age will not have had. They can have developed early maturity in some areas”.

MOVING ON



Healthy living after treatment

Now that your child is off treatment and is in the 'follow up' phase, the aim is to help your child stay as healthy as possible – to stay well and to do well in school or at work.

The effects of childhood cancer and treatment on appetite and physical activity are different for each child. If your child experienced problems with nutrition and maintaining a healthy weight during treatment, you may have given your child food supplements, and been encouraged to give them food full of calories! On the other hand some children being treated for leukaemia may have gained a lot of weight during treatment.

Now that treatment is completed, it is a good time to begin to make healthy choices about your child's diet and exercise. Most children will begin to put on weight once treatment is finished, or in the case of leukaemia, lose it when they stop taking steroids. As a parent this will be very reassuring to see. However, in order for them to maintain a healthy body in the future, returning to a healthy diet and physical activity is very important. These choices can have a positive effect on your child's health for many years to come.

A good diet and physical activity will have many benefits for children who have had treatment for cancer. These include:

- Helping to heal tissues and organs that have been damaged by the cancer and treatment
- Building up your child's strength and stamina
- Reducing the risk of developing certain types of adult cancers and other diseases in adult life
- Reducing feelings of stress and increasing feelings of well-being.

A balanced healthy diet is based on the five commonly accepted food groups which are:

- Bread, cereals and potatoes
- Fruit and vegetables
- Milk and dairy
- Meat, fish, pulses and nuts
- Foods containing fat + foods and drinks containing sugar (Foods in this fifth group are not essential to a healthy diet).

What about vitamin supplements?

Vitamin supplements are not a replacement for good eating habits. Encouraging your child to have a variety of foods from the first four groups above

every day will help ensure they have a wide range of the nutrients and vitamins their bodies need to remain healthy and function properly.

What about exercise and physical activity?

Children and adolescents should be encouraged to try to fit some physical activity into their daily routine. It is important to combine healthy eating with physical exercise.

In general, a healthy lifestyle includes, not smoking; eating a low fat, high fibre diet; exercising regularly and avoiding an excessive alcohol intake!

Protect children from sunburn using cover-up clothing and a high factor sunscreen.

What happens when my child reaches 18 years?

As mentioned previously all children who complete their treatment for cancer attend follow up clinics regularly in order to identify, assess and treat problems that may arise. Some children will have few problems in the follow up period; others may need more help including both physical and psychological support.

Problems related to cancer treatment that occur or persist when treatment is finished are known as 'late effects'. Follow up care will continue well into your child's adult life.

If your child is very young when they finish treatment, adolescence and adulthood may seem a long way off! However, as adolescence approaches, your child will grow physically and emotionally. They need to be supported in developing as much independence as possible in order for them to be able to make choices about their own health-care.

What is transition?

In some cancer centres, young adults who were treated for cancer as a child and have been off treatment for over five years, are now having their follow up visits in an adult hospital. The process of helping these young people as they move from the familiarity of the child and family environment of paediatrics to being cared for in an adult hospital clinic is called 'transition'.

You can help this process when your child is young by:

- Talking to your child to help them gain

an understanding of their cancer and the treatment

- Explaining the reasons for them coming to the follow up clinic
- Encouraging your child to ask questions and talk directly to the doctor/nurses

So they feel ready to move on they will also be supported by doctors and nurses in clinic:

- In understanding their cancer, treatment and follow up
- In gaining more independence and starting to make their own decisions
- By giving them health care advice.

Adolescent and adult long term follow up care will vary in each cancer centre. If you require any further information on 'transition', your own doctors / nurses will be able to inform you.

HELPFUL ORGANISATIONS

Cancerbackup

A national cancer charity providing information and resources for anyone affected by cancer.

Tel: 0800 800 1234

www.cancerbackup.org.uk

Cancer Research UK

National charity devoted to the causes, treatment and prevention of cancer.

Provides a range of information for anyone affected by cancer.

Tel: 0808 800 4040

www.cancerresearchuk.org

CLIC Sargent

An organisation providing information and support for children and young people with cancer and their families. Services include the Child Cancer Helpline - a free, confidential helpline providing information and support to anyone affected by childhood cancer, including family members, friends and professionals.

Tel: 0800 197 0068

www.clicsargent.org.uk

Children's Cancer and Leukaemia Group

An organisation for professionals treating children with cancer. Provides a range of information for patients and families affected by childhood cancer.

Tel: 0116 249 4460

www.cclg.org.uk

www.childcancer.org.uk

gaps:line

A listening ear service, giving emotional support to parents and carers of children with cancer and leukaemia.

Tel: 0845 121 4277

www.gaps.uk.com

Macmillan Cancer Support

UK charity offering support to people with cancer by providing expert care and practical support.

Tel: 0808 808 2020

www.macmillan.org.uk

National Alliance of Childhood Cancer Parent Organisations (NACCPO)

A national voice for parents of children with cancer working with medical, government and charity organisations to address issues affecting children with cancer and their families.

Tel: 01785 603763

www.naccpo.org.uk

Teenage Cancer Trust

Deals with all issues affecting teenagers with cancer.

Tel: 020 7612 0370

www.teenagecancertrust.org

These organisations may also be useful sources of information and support

Beyond the Cure

Website: www.beyondthecure.org

Brain and Spine Foundation

Website: www.brainandspine.org.uk

Headstrong: All about brain tumours

Website: www.headstrongkids.org.uk

Leukaemia Research Fund

www.lrf.org.uk

National Childhood Cancer Foundation Children's Oncology Group

www.curesearch.org

Medi Travelcover Ltd

www.meditravelcover.com

The Food Standards Agency

www.foodstandards.gov.uk

The Never Ending Squirrel Tale

www.squirreltales.com

USEFUL BOOKS AND BOOKLETS

- **A Parent's Guide to Children's Cancers.** Produced by the CCLG and Cancerbackup
- **Welcome Back!** A guide for teachers. Produced by Cancer Research UK
- **Children with a brain tumour in the classroom.** Produced by Cancer Research UK

- **What's the point in coming to clinic?** Produced by CCLG and Cancer Research UK
- **Aftercure: what does this mean for you?** Produced by CCLG www.aftercure.org
- **Relationships, Sex and Fertility** For young people affected by cancer. Produced by Cancerbackup
- **Childhood Cancer Survivors** A practical guide to your future by Nancy Keene, Wendy Hobbie & Kathy Ruccione. Published by O'Reilly

More CCLG publications:

- **Brothers and Sisters** - A guide for parents of children and young people with cancer
- **How to Help Brothers and Sisters** (for adults)
- **My Brother has Cancer** (for children aged 3-9)
- **When your Brother or Sister gets Cancer** (for young people aged 9-18)
- **Grandparents:** A guide for grandparents of children and young people with cancer
- **Ben's Bone Marrow Transplant**

For CCLG publications go to www.childcancer.org.uk to download, or order a booklet, or contact the CCLG at the address on the back cover. Multiple copies of the brothers and sisters, and grandparents booklets are available from CLIC Sargent – details on page 29.



“The end of treatment is a good time for everyone (or it was for us) – he is 100% healthy and we’re so lucky and thankful!”



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CANCER RESEARCH UK



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Fax: 0116 254 9504

Email: info@cclg.org.uk

Registered Charity No: 286669

**CCLG leaflets are available to
download from www.childcancer.org.uk**