Sport and Exercise for Children and Young People with Cancer: A Parent's Guide

Children's Cancer and Leukaemia Group

CCLG

www.cclg.org.uk

This booklet was written by Sue Ablett and Ginny Macintyre in conjunction with the CCLG Publications Committee, comprising multiprofessional experts in the field of children's cancer. Physiotherapists, Michelle Payne (Royal Marsden Hospital) and Mary Jones (Birmingham Children's Hospital) provided additional expert advice.

Designed and printed by Greenshires Group Ltd.

Originally published by CCLG November 2011.
Revised and reprinted November 2013.
Review date November 2016.

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Introduction

This booklet is for parents of children and young people with cancer. It gives practical advice that may help in terms of approach to sport and exercise both during and after treatment. It also touches on some of the concerns that we know arise, and will hopefully provide some answers to the many questions you may have. Booklets can never be a substitute for discussion with the team treating your child: every case will be different, so do seek advice if you have particular concerns or questions.

Although written principally for parents, the content of this booklet will be equally useful for other carers or family members, teachers and those involved in sports clubs, but also for the children and young people themselves. Feel free to pass the booklet on to others who you think might be interested, or who would benefit from it. For further copies contact CCLG at the address given, or download from www.cclg.org.uk .

I am particularly grateful to those parents and survivors who have provided quotes, based on personal experiences, and also reviewed copy. Some quotes have been taken from articles previously featured in *Contact* magazine. Where that is the case the full article is referenced. All previous articles can be accessed from the CCLG website. The illustrations included in this booklet are not of any of the children referred to in the quotes.

Sponsorship of this booklet came from very generous support from friends and colleagues of my 2010 London Marathon run. The position didn't matter, nor did the time, though I was pleased with it. For me, taking part was a lifelong dream; the day was about achieving something I had always wanted to do, and enjoying every single minute of the experience (yes, running 26 miles can be fun!). I'm delighted that, as a result of my run, we are able to sponsor this CCLG publication

Sue Ablett

Sue Ablett
CCLG Executive Director
(1992 – Feb 2013)

ps - Many thanks to Tracy Playle whose London Marathon 2013 sponsorship funded this reprint.

> There is sport during and after cancer. I believe it has helped my son enormously to keep positive and feel good about himself. He remained extremely well whilst on maintenance therapy, still doing a lot of sport despite monthly doses of chemotherapy and steroids. He will not give up and sport helps him to do this.

Ginny Macintyre, mother of Alex, diagnosed with ALL,
Contact Issue 35, Summer 2007

Contents

Why is sport and exercise important?

The ability to take part in sport and exercise is something we take for granted; it is very much part of normal life for children and young people. This may include team or individual sports, at a competitive level, either through school or membership of specialist clubs, or something as simple as just riding a bike or kicking a ball with friends.

Sport and exercise are important because:

- they can increase and maintain our level of fitness
- they help us maintain a healthy weight (your child may gain or lose weight during treatment)
- they improve our sense of well-being and self-confidence
- particularly with team sports, they improve our sense of belonging.

Finding a way to continue with an activity that your child has always enjoyed may require some adaptation as they go through treatment, or even afterwards.

The benefits of sport and exercise

There are many known benefits to incorporating general exercise into the pattern of daily life. Regular exercise releases hormones called endorphins, which contribute to a sense of 'feeling good'. For children and young people with cancer, whose lives have been turned upside down by their diagnosis, and who may have spent long periods in hospital, this can be very beneficial. Some exercise is also known to enhance good patterns of sleep, has been shown to decrease pain, and also to increase appetite and ease the problems of constipation, both of which may be related to the treatment being given. Weight bearing exercise can benefit a child's bone density – as reduced bone density is a known side effect of some treatments.

A healthy lifestyle, with regular exercise, can help prevent illness, though this cannot be guaranteed.

> What about sport, was one of the many questions we asked the doctors. Rugby was definitely out – but what about football, hockey, cricket?
>
> **Ginny Macintyre,** *Contact* Issue 35

> We introduced Craig to horse-riding for a few months following his treatment to improve his balance. He developed a lovely relationship with the horse he rode every week and really looked forward to his lessons.
>
> **Lesley Ingram,** mother of Craig, diagnosed with a brain tumour

> Before my treatment I was intending to apply to University to study sports science, and I was midway through a football coaching qualification. Losing a limb forced me into a major rethink of where I was going in life, and what I would be limited to... I completed my coaching course. I might not be able to walk as far as normal people, or run, but I can still be involved. In fact, I think I'm more involved with sport now than ever before.

Matt Short diagnosed with bone cancer, aged 17, *Contact* Issue 52, Autumn 2011

Does a diagnosis of cancer mean the end of sport and exercise for my child?

No, it doesn't. Inevitably, however, a diagnosis of cancer raises all sorts of questions, including whether or not your child will be able to take part in sport and exercise, now or in the future.

There will be practical issues that you will need to consider and these are outlined in this booklet. There may be some limitations, or adaptations required, either temporary or longer-term, depending on the type of cancer that your child has, what stage they are at in their treatment and, of course, the type of sport in question.

Physical activity is a really important part of recovery following surgery to remove a brain tumour. Instruction will be given about what type of activity to begin with, and how to increase the activity.

Having a central line is probably the main reason why parents are reluctant to encourage their child to take part in P.E. and other sporting activities. Children are advised not to go swimming when they have a central line, because of the risk of infection, or take part in contact sports (such as rugby or judo), because of a risk of the line being pulled out.

If your child is a keen swimmer you could ask the medical team whether a 'port' rather than a 'line' is possible so that your child can continue swimming. They will explain the difference and the reasons why one might be better than the other.

Even if your child is offered a 'port' there may still be times when they are advised not to swim, for example, if blood counts are low, risk of infection or if they are generally unwell.

Contact sports, such as rugby and judo, that involve opponents grabbing at loose clothing, barging into each other and knocking each other to the ground, are too big a risk if your child has a central line.

Other games and activities can still take place and advice can be given about how to participate safely. As a parent you can help by making sure the line is well secured prior to play, games or activities. Ask the nurses at your local centre for advice. It may be that a tighter T-shirt or extra Tubi-grip stocking is all that is needed to give your child confidence to take part.

Not all children are sports mad. Your child may not have been particularly interested in sport prior to being diagnosed with cancer. Exercise may, however, be considered an important part of their rehabilitation in terms of general health and wellbeing. This is something that the team treating your child will discuss with you, and advise you about.

> Jenny is a keen rider and was out competing on her pony two weeks before she was diagnosed. Being told that riding was likely to be out of the question during the two years of chemo was a shattering blow on top of all the other changes we were having to face. Rather than putting Shandy out 'on loan' we decided to keep him and see what happened next.

Julie Summersgill, mother of Jenny diagnosed with ALL, *Contact* Issue 37, Winter 2007

Am I being over-protective?

Inevitably, following a diagnosis of cancer, most parents feel a need to protect their child. Parents may feel overly anxious about their child taking part in sports which can lead to injury. The desire to wrap your child in cotton wool may be a strong one. There may be concerns that by allowing your child to take part in sport you make matters worse. In some circumstances this can lead to parents adopting an overly cautious approach.

Equally, there may be some parents who are so determined that their child should carry on with normal activities that they fail to take reasonable precautions to reflect their changed circumstances.

Others will take a sensible and more balanced approach, and need to be supported in doing this. It may be that sport and exercise was something the whole family used to do together – perhaps family cycling or walking trips; there really is no reason why that can't continue, although maybe with some adaptation.

There needs to be a balance. There will be days when your child may feel more or less able to undertake sport or exercise. It will be important that you provide encouragement when they can, and support when they can't.

If you are in any doubt about whether or not your child should take part in sport and exercise, then do discuss it with the team treating your child. There may be occasions, for example, when the child is at high risk of infection, when contact with other children may need to be avoided. Some of these issues are covered in the section, Practical Tips, on page 20.

If your child has been treated for a brain tumour swimming may be appropriate, but no diving or jumping in for a number of weeks after surgery, and this can only be started when your child's wound is fully healed. If you have any concerns, make sure you discuss them with your child's neurosurgical team.

> Its tempting to wrap these children in cotton wool – every parent feels like this. Luckily for me, and Alex, he wasn't having any of this. The nurses and doctors backed us all the way.
>
> **Ginny Macintyre,** *Contact* Issue 35

> When Ben was diagnosed with a spinal cord tumour, a friend lent us a bike holder, so that he could cycle his bike statically indoors to try and build up his strength. He soon got on and kept building on targets – this was a huge boost to Ben physically and mentally.
>
> **Caroline Cross,** mother of Ben, diagnosed with a spinal cord tumour

I was 17 when I was diagnosed with bone cancer and had a below the knee amputation. That was 22 years ago now and, over the years, I have come to realise that I am capable of doing anything that I put my mind to…
Despite being a county swimmer before my operation, within six months I was swimming quicker with one leg than before when I had two. Eighteen months later I went to my first Paralympic Games.

Marc Woods
Contact Issue 44, Autumn 2009

Eventually, Jenny's consultant agreed to let her get back on her pony. We had strict rules, involving the use of a hat and body-protector, and she was only allowed to walk or trot, with definitely no jumping. This we did and, after weeks of being isolated in a hospital room, the sight of Jenny smiling on her pony was the biggest tonic I can remember…
Jenny's team deserve a big thank you, especially for letting Jenny continue riding.

Julie Summersgill,
Contact, Issue 37

Ben went wheelchair ice-skating. I hadn't seen him laugh for such a long time. His friends pushed him round. Those that were good skaters whizzed him round the corners at great speed. This helped to show him that, although he was in a chair, he could still participate in fun activities with his friends.

Caroline Cross, mother of Ben

How can I help and support my child?

Your child will be going through all kinds of emotions following a diagnosis of cancer. Inevitably they will also suffer the physical effects of their cancer and the treatment they are receiving. They may feel different and cut off from friends and normal activities. They may experience a sense of frustration from the fact that "I can't play games any more but all my friends can."

It is important that you, and your child, follow the advice of the medical team. They will be intimately involved in your child's care, and will know the times when it may or may not be appropriate to take part in sport or other exercise. They will also be keen to see your child return to, and maintain, a good level of general fitness. The goal at end of treatment will be a return, wherever possible, to normal activities, albeit possibly with some adaptations for any longer-term disabilities. It is important that you follow advice about when to start exercising again, how much to do at a time, and when you may need to stop for a while.

While taking part in sporting activities may be out of the question for a while, parents can still help by encouraging their child's friends to provide updates on team progress, for example. In that way they are not totally out of the loop. Watching sport and participation on the sidelines, without necessarily playing, is a good way to keep in touch, both with the game and with team-mates. If you have concerns about whether your child should avoid crowds while on treatment or neutropenic (low white cell count), do discuss this with the medical team.

At the same time as encouraging their child to return to sporting activities that they may have previously enjoyed, parents should realise that, particularly as children get older, they may naturally outgrow or just become bored with a previously much enjoyed activity. This may stem from a feeling that they have done something for long enough and want to try something different: the influence of their peers can be important at such times. It is easy to assume that all decisions are cancer-related, but this need not necessarily be the case.

We are about to come to the end of our time with horses as Jenny is wanting to do other things now, but they were a vital part of her recovery, and getting out of the hospital into a muddy field was a vital part of my 'recovery' too!

Julie Summersgill, mother of Jenny

Setting and achieving goals

For parents, and for the child with cancer, having goals to aim for as you go through treatment or embark on life beyond treatment, will be important.

This will include setting personal goals and achieving targets, even if the goals and targets are very different to ones you might have originally thought of before diagnosis.

- They do not have to be about climbing the highest mountain, or doing the longest walk, or the fastest swim.
- It may be about just taking the first steps again.
- While it is important to have a final goal in mind, and to know how the bigger picture looks, it is essential that this is broken down into bite-sized goals, which are more likely to be achievable.
- This process will require constant evaluation: goal posts can shift, sometimes as a result of the cancer treatment or other cancer-related issues, and sometimes because of dips along the path, which may be totally unrelated to the cancer.
- It may sometimes be a question of two steps forward, and one step back.
- A step back should not be seen as failure. If it does happen it is still important to focus on the end goal, and to look back at progress that has been achieved in striving for that goal.
- By setting realistic goals, which are achievable, the whole family can benefit from a real sense of satisfaction. It may help to write your goals down so that you can make a note when you have achieved them.
- After the devastation of diagnosis and treatment, there will be a real sense of pride for parents, watching their child's achievements, whatever they may be, and however big or small.

> When our family climbed our first mountain with a wobbling Amy in tow, the adrenalin rush was terrific. Here we were, survivors all, back on top of the world again!
>
> **Jane Redman,** mother of Amy, diagnosed with a brain tumour,
> *Contact* Issue 34, Spring 2007

> Anne was diagnosed at the age of three. She started swimming lessons when she was four, and learnt to swim shortly afterwards. She is now one of the strongest swimmers in her class. She also learnt to ride her bike without stabilisers during maintenance.
>
> **Neil Ranasinghe,**
> father of Anne, diagnosed with ALL

Who else can help?

Apart from parents, help and support can come from a range of sources.

Siblings can play a vital role, often without realising how much they are helping. They can encourage the sick child to start kicking a football in the garden, have a short run in the park, or get back on their bike.

Among those who can support and encourage will be school friends, school and P.E. teachers, sports coaches etc. A child may still be able to take part in sport, but with some concessions, such as maybe only playing for part of a game, or they may need subtle help in some way, such as getting to and from the pitch. It is important to remember that, while needing help, the child will not want to seem any different from their peers. They certainly won't want an over-anxious parent jumping up and down on the touchline!

If a child with disabilities is able to play in a team, they may gain a much-needed sense of belonging and some confidence at being accepted by others. If the experience is a positive one, the joy of parents at seeing their child back at the heart of a team will be more important than the outcome of any game.

There is a risk, however, that the experience may be more negative, either for the child or the parents, for instance if the child is not able to fully participate, or if their condition is not known about or understood by other team members. Full integration may take time. In the meantime, there may be alternatives, which will still ensure that the child does feel included.

There may be an important role to be fulfilled as referee, scorer, or line judge, commentating, or perhaps writing an end of match report. Any of these activities would be a good way of reintroducing the child to the sporting environment until they were physically able to fully participate.

Following the discovery that one of their pupils had been diagnosed with leukaemia and would need treatment over three years, one school chose a novel way to involve all pupils in a sporting exercise, which also proved a huge fundraiser.

> I stood on the touchline, not daring to watch, but having to in case he needed me, wanting to shout to the other players to treat him gently! But they didn't know he was ill, and Alex certainly wouldn't have wanted them to know.
>
> **Ginny Macintyre,** *Contact* Issue 35

> After Alexander was diagnosed, the school felt very strongly that his condition offered a wonderful opportunity for the school to make a difference for other children in his position. 'Legging it for Leukaemia' was organised with every one of the 340 pupils in the school taking part. The organisers had discussed three to four laps for the younger and perhaps 10 to 15 for the older children. Astonishingly a number of children ran in excess of seven miles, including Alexander.
>
> **Catrin Sherwood**, Deputy Head,
> Rosemead Preparatory School, London
> *Contact* Issue 38, Spring 2008

> I have managed to do similar activities to those I got up to before. They are now far more of a challenge. Just trying to do them is very satisfying. I have mastered riding my bike without adaptations. I have walked up Mount Snowdon three times, using my crutches and taking a different route each time. And no, I didn't get the train down!

Cancer survivor, **Lindsay Shearer**, diagnosed with a bone tumour, *Con*tact Issue 45, Winter 2009

Who else can help?
continued

Staff in the treatment centre will be happy to liaise with your child's school and provide practical advice and support on what might be appropriate for a particular child, at any particular time.

The physiotherapist

The physiotherapist will be an important member of the team treating your child. A common problem experienced by the majority of children diagnosed with cancer at some point will be muscle wasting or weakness. This may be the result of long periods in bed, inactivity, the effect of steroids or other chemotherapy drugs, or be related to the particular type of tumour. Aching muscles may also be a problem. The physiotherapist will be able to provide support in terms of help to build up muscles, and also maintain flexibility in the joints. They may also be able to give you a programme of exercises that your child can do at home. Physiotherapists will also help with any coordination and balance issues that your child may have.

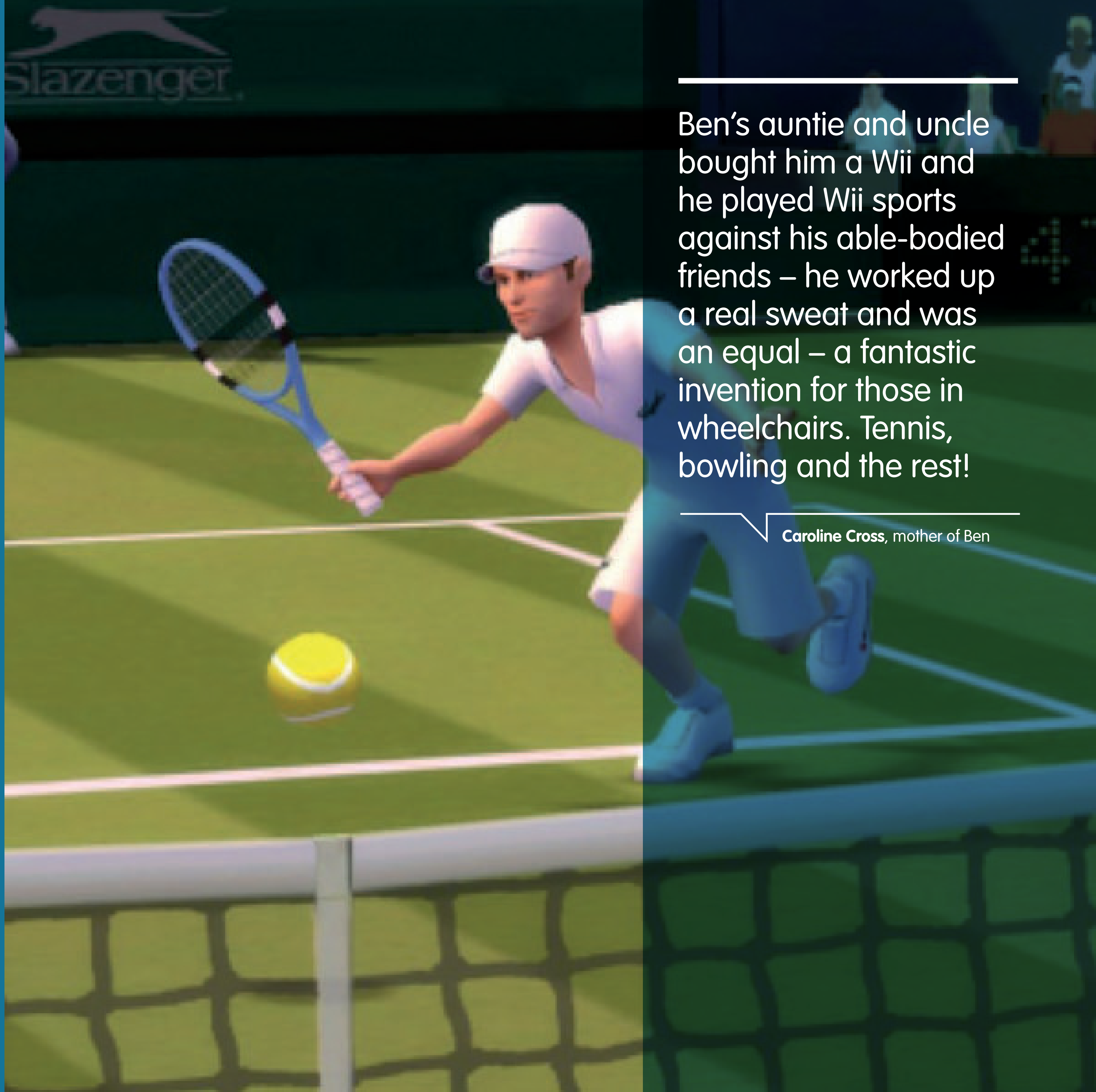
Your physiotherapist, or other members of the medical team, may have details of organisations locally, such as gyms or swimming pools, that offer facilities or special programmes for those returning to exercise after a period of illness.

You will also be able to obtain more specialised information, such as that relating to sport for the disabled and how that is organised.

Practical tips

The following practical tips are all very general. You will be given specific advice by the medical team on what your child can do. This will vary significantly depending on the nature of their diagnosis, the type of treatment being given, and the timing, and the type of sport being considered. Your child's medical team is the best source of information, and you should contact them if in doubt about any issues.

- Build activity or exercise into your child's daily routine. This may need to be built up slowly and sensibly. For instance, if you live a reasonable distance from the school, you may need to drive all the way to start with, then after a while drop your child off so that they have a little walk, gradually extending the distance of the walk. Knowing when to stop for a while is important.
- Encourage safe exercise. Incorporate warm up, remember little and often at first. Increase activity as a family, for instance ball games or a Sunday morning walk or swim. Use a home video system to play games. Discuss pacing activities – the physiotherapist can offer advice with this.
- Be aware of blood and platelet counts. If haemoglobin (Hb) counts are too low, your child will not be getting sufficient oxygen, and exercise may result in fainting or breathlessness. Low platelet counts may increase the risk of bruising and bleeding. Parents very quickly learn the importance of blood counts, and the medical team will give you more advice about this.
- Take care with infection. If they have an infection, your child should not exercise over and above the daily routine. If your child has a temperature he/she should not exercise.
- Watch out for fatigue. There are a number of factors that can cause or contribute to fatigue. It affects people in different ways, and at different times. You need to ensure a balance between activity and rest; be aware of your child's limitations and allow 'time out' if needed. Gentle, graded exercise is a good way of managing and overcoming fatigue and increasing energy levels. The team will be able to advise about fatigue management.
- If your child is feeling unwell, or has new or unexplained pain, seek advice before allowing him/her to resume sport or exercise.
- Ensure that your child takes reasonable precautions to cover up in the sun.
- Make sure that your child drinks enough while exercising.



> Ben's auntie and uncle bought him a Wii and he played Wii sports against his able-bodied friends – he worked up a real sweat and was an equal – a fantastic invention for those in wheelchairs. Tennis, bowling and the rest!

Caroline Cross, mother of Ben

Practical tips
continued

- Make sure that your child's calorie intake is appropriate for their level of activity
- Ensure that your child has appropriate, and suitably protective, footwear or other clothing, for the activity being undertaken.
- For children who have had brain tumours, it is important to ensure that the child does not fall over or bump their head.
- Many children will have a central line fitted at some point during their treatment. You should ask for specific advice about this, particularly in relation to swimming and other water sports.
- If your child has a prosthesis in place after surgery for bone cancer it is very important that you seek advice from the surgical team about which types of exercise would be considered appropriate.
- After treatment is finished, some children will have no long-term problems and may quickly be able to resume their previous activities. Parents should be aware, however, that this may not always be the case. Progress post-treatment may depend on the type of tumour, and how much the child was able to maintain a good level of fitness while on treatment.
- Those children with continuing difficulties or disabilities post-treatment, may still be able to undertake general exercise. It might be necessary, however, to explore alternatives to actually taking part in sport. This could include continued involvement through developing an interest in watching a team; refereeing or coaching others; involvement with supporters clubs, or perhaps through a career in sports management.

> We have to adapt. Because of his brain tumour, tennis is very difficult for Craig. He has vision, balance and coordination issues. When we play tennis as a family, Craig is allowed 2 (or more!) bounces of the ball. He keeps missing but the rest of us encourage him, so he enjoys it. When he hits it, he's ecstatic!
>
> **Lesley Ingram** , mother of Craig

Useful contacts and other sources of support

There are a number of organisations that provide activity holidays for children and young people with cancer, or for survivors: some are national and some operate more locally; some cover a wide range of activities, while others are more specialised. These holidays are highly rated by those who are able to attend: they may provide the opportunity to try new physical activities, but they also fulfil an important function in addition. Pushing boundaries, building confidence, getting young people working and playing together, spending time outdoors, providing a sense of achievement and, above all, having fun, are some of the additional benefits.

Barretstown - a specially designed camp that provides therapeutic recreation for children with serious illnesses, and their families.
www.barretstown.org

Camp Quality UK - provides life-changing holidays for children with a potentially life-limiting condition.
www.campqualityuk.org.uk

Ellen Macarthur Trust - aims to support, empower and enliven children suffering from cancer by introducing them to the joys of sailing on the sea. www.ellenmacarthurtrust.org

Over the Wall Camp - provides life-changing camps for children with serious illness. www.otw.org.uk

Youth Cancer Trust - provides free, fun activity-based holidays for young people (aged 14-30) suffering with cancer or any other malignant disease. www.yct.org.uk

Details of other organisations offering holidays can be obtained from the Childhood Cancer Parents Alliance
www.childcancerparents.org/info/breaks.html

Other useful organisations include:

British Swimming Disability source of information about swimming with a disability
www.swimming.org/britishswimming/disability-swimming

Cyclists Fighting Cancer – awards bikes, tandems and specially adapted trikes to children and young people affected by cancer. www.cyclistsfightingcancer.org.uk

Transplant Sport UK – information about the UK Transplant Games. www.transplantsport.org.uk

Climbing Out – runs 5 day residential outdoor activity programmes. www.climbingout.org.uk

> We have been in the fortunate position of being able to give Craig the chance to take part in a wide variety of sports over the years. Sport has been a great way for him to keep fit and healthy, as well as a springboard for forging new relationships.
>
> **Lesley Ingram**, mother of Craig

> I took up golf. I have competed in two 10k runs. The crowd spurred me on and I felt a huge sense of achievement. I started playing for a disabled football team, competing in tournaments and making a lot of new friends. I love new challenges and I am not scared to give things a try. I do not let my disability define who I am or what I am capable of.
>
> **Craig Ingram**

> This is a great booklet. I wish it had been around when Katie was ill as I was definitely an over-cautious mum!

Fiona Adams, mother of Katie,
diagnosed with Wilms tumour

Winner of the 2012 BMA
Patient Information Award
for the Self-care category

Winner of the 2012 Association
of Social Care Communicators
Publications Award

If you have any comments on this booklet, please contact us:

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