



Children's  
Cancer and  
Leukaemia  
Group

# Keeping active during and after treatment

A parent's guide to physical activity, sport and exercise for children and young people with cancer



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## About this booklet

This booklet is for parents of children and young people with cancer. It gives practical advice that may help when thinking about activity levels both during and after treatment.

It also covers some of the concerns 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, 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.

*“This is a great booklet. I wish it had been around when Katie was ill, as I was definitely an over-cautious mum!”*  
**Fiona, mother of Katie diagnosed with Wilms' tumour**

**Front cover:** Edie, diagnosed with a brain tumour, and her brother.

# Contents

Why is it important to keep active?.....	4	How do we start?.....	12
What activity can my child do?.....	6	Who else can help?.....	14
Am I being over-protective?.....	9	Practical tips.....	16
How can I help and support my child?.....	10	Useful contacts and other sources of support.....	18



*“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 would not give up and sport helped him to do this.”*  
**Ginny, mother of Alex diagnosed with ALL**

## Why is it important to keep active?

Being able to take part in sport and exercise is something we take for granted and is part of normal life for children and young people. This may include team sports and clubs or something as simple as riding a bike or kicking a ball about with friends.

The treatment children go through for cancer can be very demanding physically. Chemotherapy itself can have side effects such as pain, fatigue and muscle tightness. Certain drugs can limit the amount of stress the heart can be put under, and others can affect the peripheral nerves causing loss of movement or sensation in their hands. This can lead to difficulties with balance and body self-perception. Not only can all of this make keeping active more difficult, practical reasons such as room isolation, being attached to drips and having a central line can also have an effect.

### Physical activity can help by:

- helping your child stay fit and well during treatment
- improving physical function and energy levels for taking part in everyday activities, like climbing the stairs, going to school or playing with friends
- improving your child's sense of wellbeing and self-confidence through the release of endorphins (feel-good hormones) from exercise
- keeping your child at a healthy weight
- helping your child to feel they belong, particularly with team sports
- helping to maintain your child's bone density
- helping to relieve constipation
- improving sleep patterns so that your child is physically tired at bedtime



“I had always been active and running was my passion. It was my lifeline during treatment and it gave me back the control I needed when my life was spinning out of control.”  
**Gemma, diagnosed with lymphoma aged 24**



“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, 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, diagnosed with bone cancer aged 17**



## What activity can my child do?

A diagnosis of cancer raises many questions as to how much your child can take part in sport and exercise.

There will be practical issues to consider and there may be some limitations, or adaptations, either now or in the long term, depending on the type of cancer your child has, what stage they are at and the type of sport in question.

### What if my child has had surgery?

Physical activity is a really important part of recovery following surgery and specific instructions will be given.

Following surgery for a brain tumour, a child may be unable to participate in contact sports.

Following surgery for a bone tumour in the leg, there may be restrictions on how much weight can be put on their leg and how much they can move their joints.

### Can my child go swimming?

If your child has a central line fitted, then they are advised not to go swimming because of the risk of infection if it gets wet.

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 differences between the two and the reasons one might be better than the other.

However, 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. Only swim in properly chlorinated pools with filters. Do not swim in ponds, rivers, the sea or any other open water or unfiltered private pools.



“Despite taking daily oral chemotherapy, Edie continues to join in school sports when she can and recently made her debut in the school football team. We even managed to find a bandana to match the school colours, to the envy of her team mates.”  
Cate, mum of Edie diagnosed with a brain tumour aged six

### Can my child take part in contact sports?

Contact sports such as football, rugby or martial arts which involve players grabbing at loose clothing, barging into each other and knocking each other to the ground, are too big a risk and not usually advised if your child has a central line as it could be pulled out. However, your child can still keep up their football or rugby skills at their local park where they can kick a ball about and shoot some penalties! Children with entriculo-peritoneal shunts to drain fluid off the brain should not take part in contact sports involving tackling or wrestling and should not head balls.

### What activities can my child take part in?

Other games and activities can still take place and your child's medical team can give advice about how to participate safely. Going for a family bike ride, walking to school and playing dance games with friends are all things children can enjoy.

Taking part in activities that are fun and enjoyable will help to motivate and encourage your child to take it up long term and keep taking part.

### What about sports, like tennis, horse riding, cricket, athletics, gymnastics or Wii sports?

Several things are important here. Is there a central line and could it get damaged? Check with the surgical team about how long to wait after an operation before doing these.

If your child has had brain surgery, ask the surgical team what your child can do after the operation, and tell them what they usually do. Avoid any sport where they may fall, or be struck by the ball, equipment or players, if platelets are low after chemotherapy.

If they are immunosuppressed then avoid stables, straw and 'mucking out' where your child may be exposed to fungal spores. Horse riding outside is ok.

### What about younger children going to soft play centres and outdoor playgrounds?

Be cautious if your child has low platelet counts, otherwise normal play should be fine.

**Not all children are into sports. Your child may not have been particularly interested in sport before being diagnosed with cancer. Exercise may, however, be considered an important part of their rehabilitation in terms of their general health and wellbeing.**

This is something 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 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, mother of Jenny diagnosed with ALL**

### Trying to build small amounts of physical activity into the day can be a good way to get started:

- Using the stairs instead of the lift when visiting the hospital
- Asking your child to push their wheelchair until they need a rest then sitting in it
- Encouraging your child to get their own drink from the kitchen rather than asking you

*“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, mother of Amy diagnosed with a brain tumour**



*“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, father of Anne diagnosed with ALL**



*“After finishing radiotherapy and beginning chemo, Edie began to build up her strength and was delighted to re-join her disco dancing troupe! She even led them in a two-hour non-stop danceathon to raise funds for research!”*  
**Cate, mum of Edie diagnosed with a brain tumour aged six**

# Am I being over-protective?

Following a diagnosis of cancer, most parents want 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. You may be concerned that allowing your child to take part in sport may 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 their child should carry on with normal activities that they might fail to take reasonable precautions to reflect their changed circumstances. Others will take a more balanced approach, and may need to be supported in doing this. If sport and exercise was something the whole family used to do together such as 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 your 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 pages 16-17.

A young boy with a prosthetic left leg is running on a red track. He is wearing an orange t-shirt with 'northern rock' written on it and dark shorts. The image is framed by a dotted circular border.

“It’s tempting to wrap 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, mother of  
Alex diagnosed with ALL**

## How can I help and support my child?

Your child will be going through all kinds of emotions following a diagnosis of cancer. They will also suffer the physical effects of their cancer and the treatment they are receiving.

Your child may feel different and cut off from friends and normal activities. They might be frustrated they can't play games any more but all of their friends can.

It is important you, and your child, follow the advice of the medical team. They will be 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 your child should start exercising again, how much to do at a time, and when they may need to stop for a while.

While taking part in sporting activities may not be possible, particularly in the initial stages of treatment, you can help to reduce the isolation your child may feel, for example by encouraging your child's friends to provide updates on team progress.

Watching sport from 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 is neutropenic (low white cell count), do discuss this with the medical team.

At the same time as encouraging your child to return to sporting activities they may have previously enjoyed, parents should realise that, particularly as children get older, they may naturally outgrow or just become bored with an activity they previously enjoyed. This may stem from a feeling 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 all decisions are cancer-related, but this may not necessarily be the case.



*“Sitting around makes me feel bored and sad. I feel better when I dance or go out on my bike. Even though I can feel really tired afterwards, it makes me feel happy to join in.”*  
**Edie, aged 10, diagnosed with a brain tumour aged six**

“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 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, diagnosed with bone cancer aged 17**



“Even though I was very fit because of my gymnastics, keeping active made tolerating the chemo a bit better and gave me something to fight with when I had my stem cell transplant. Cancer took away my leg and part of my lung but it increased my drive to show what oncology kids can do.”

**Kieran, aged 16, diagnosed with bone cancer aged 12**



“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, mother of Jenny diagnosed with ALL**

## How do we start?

For parents, and for the child with cancer, having goals to aim for as they 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.

- Goals 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 this is broken down into bite-sized goals, which are more likely to be achievable.
- This process needs 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 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 you can make a note when you have achieved them.
- After the devastation of diagnosis and treatment, you may feel a real sense of pride, watching your child's achievements, whatever they may be, and however big or small.

*"We have to adapt. Tennis is very difficult for Craig because of his brain tumour. He has vision, balance and coordination issues. When we play tennis as a family, Craig is allowed two (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, mother of Craig diagnosed with a brain tumour**

## An example of how to set a 'SMART' goal:

**GOAL:**  
Ride bike to the park  
with brother

### Example exercise plan

- Heel raises in shoes
- Seated exercise bike in physiotherapy
- Calf stretches 2 x daily
- Balance exercises
- Strengthening exercises

S Specific	M Measurable	A Achievable	R Realistic	T Time
What exactly do you want to achieve? (What, where, why)	How will you know when you have reached your goal?	Can it be done? Will you need to make any adaptations?	Make sure it isn't too much in one go.	When do you want to achieve this goal?
Which park? Something he loves, always used to do with family on weekends. Currently unable as gets too tired.	Will be able to get there in one go without stops.	May need to start with stabilisers May need to take rests along the way	How far is the park? Are there hills?	6 weeks

“When Ben was diagnosed with a spinal cord tumour, a friend lent us a bike holder, so 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, mother of Ben diagnosed with a spinal cord tumour**

## Who can support your child?

Help and support for your child can come from a range of sources.

Brothers and sisters can play a really important part by encouraging their sibling to kick a football about in the garden or going on a bike ride.

School friends, school and PE teachers, sports coaches and clubs can all support and encourage your child to keep up activity levels. Your child's hospital team will be happy to liaise with your child's school and provide practical advice and support on what your child needs at any particular time.

Your child may still be able to take part in sport but with some flexibility, such as maybe only playing a part of the game or may need some subtle help getting to and from the pitch. It is worth remembering that while your child may need help, they will not want to seem different from their friends (or have over-anxious parents jumping up and down on the sideline!).

There is a risk your child or you as parents may have a negative experience, particularly if your child is not able to fully participate, or their condition is not known about or understood by other team members. Full integration may come in time, however, in the meantime there may be alternative roles in which your child can still play a part and feel included, such as being a referee, line judge, commentator or even writing an end of match report! Any of these are a good way of reintroducing your child to sport until they are able to fully participate.

### If your child has a disability

If your child is still able to play in a team, they will gain a much needed sense of belonging and confidence at being accepted by others and the experience for the whole family will be a positive one. There are many local charities who offer coaching and sport facilities, so please search online for your area. For more information, please see page 18.

*“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. ‘Leggin 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, Deputy Head, Rosemead Preparatory School, London**

## The role of a physiotherapist

A physiotherapist is an important member of your child's hospital team who helps children on treatment stay as active as possible. Cancer treatment can be very physically demanding and, if difficulties arise, they will assess and monitor your child and offer help and support.

Most children will experience symptoms which will affect their activity levels, most commonly muscle wasting and weakness. Your child's physiotherapist can recommend exercises to strengthen muscles, improve muscle length and keep joints flexible. They can also give you a programme of exercises your child can do at home. They will offer advice and education about re-integration into sport and to help your child exercise safely.

Fatigue, or extreme tiredness, can affect most children with cancer and can be very debilitating, stopping children from doing the things they love. It can also continue after treatment has finished and may take a long time to resolve. A physiotherapist can help manage fatigue with the right integration, graded exercise and expert guidance.

Your child's physiotherapist or hospital team may have details of local organisations such as gyms or leisure centres that offer facilities or specialist programmes for those returning to exercise after being ill, as well as information on disability and sport.

**Occupational therapists** may also be involved in your child's care. They can help with managing fatigue, and with enabling participation in activity such as play.

“ I love the fact a huge part of my job is to make activity fun. I always try to make activity part of everyday routine and involve the whole family. It is my job to help each child reach their potential and also to troubleshoot when times are challenging.”

**Lucy Buckley, Paediatric Physiotherapist**



## Practical tips

The following practical tips are 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, 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.



## KEEPING ACTIVE

- 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 they have a little walk, gradually extending the distance of the walk.*

- Knowing when to stop for a break during an activity, or rest altogether for a few days, is important.
- Make activity fun and try things as a whole family.
- Start with small goals and gradually build up.
- 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 you seek advice from the surgical team about which types of exercise would be considered appropriate.
- 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. Discuss pacing activities – the physiotherapist can offer advice with this.*

## HEALTH

- 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.

If your child has advanced or incurable cancer, keeping active, where possible, can have benefits. It can help to maintain independence, sustain quality of life, bring a sense of normality and provide opportunities for quality time with family and friends.

## LIFESTYLE & NUTRITION

- Ensure your child takes reasonable precautions to cover up in the sun.
- Ensure your child has appropriate, and suitably protective, footwear or other clothing, for the activity being undertaken.
- If your child has had a brain tumour, it is important to take extra care during activities where your child might fall over and bump their head.
- Make sure your child drinks enough while exercising.
- Make sure your child's calorie intake is appropriate for their level of activity.

## AFTER TREATMENT

- After treatment is finished, some children will have no long-term problems and may quickly be able to resume their previous activities. However, this may not always be the case. Progress after cancer treatment may depend on the type of tumour, and how much your child was able to maintain a good level of fitness while on treatment.
- If your child has continuing difficulties or disabilities after treatment, they may still be able to undertake general exercise. It might be necessary, however, to explore alternatives to taking part in sport, such as continued involvement through watching a team; refereeing or coaching; involvement with supporters clubs, or perhaps a career in sports management.
- In the longer term, exercise can help to reduce the occurrence or impact of late effects (side effects of treatment that may be experienced years after it ends), such as reduced bone density, heart and lung problems and psychological effects.

## 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

[www.barretstown.org](http://www.barretstown.org)

A specially designed camp that provides therapeutic recreation for children with serious illnesses, and their families.

### Camp Quality UK

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

Provides life-changing holidays for children with a potentially life-limiting condition.

### Ellen Macarthur Trust

[www.ellenmacarthurtrust.org](http://www.ellenmacarthurtrust.org)

Aims to support, empower and enliven children suffering from cancer by introducing them to the joys of sailing on the sea.

### Over the Wall Camp

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

Provides life-changing camps for children with serious illness.

### Youth Cancer Trust

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

Provides free, fun activity-based holidays for young people (aged 14-30) suffering with cancer or any other malignant disease.

## Other useful organisations include:

### Sport England

[www.sportengland.org](http://www.sportengland.org)

Aims to increase the number of people doing sport and activity – no matter what their background, ability or age.

### Cyclists Fighting Cancer

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

Awards bikes, tandems and specially adapted trikes to children and young people affected by cancer.

### Move Charity

[www.movecharity.org](http://www.movecharity.org)

Dedicated to supporting children & young people living with cancer through the power of exercise and sport.

### Transplant Sport UK

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

Information about the UK Transplant Games.

### Climbing Out

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

Runs 5 day residential outdoor activity programmes.

### Disability sport

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

A guide to organised sport and recreational opportunities for people with disabilities at both local and international levels.

### UK Sport

[www.uk sport.gov.uk](http://www.uk sport.gov.uk)

The nation's high performance sports agency investing in Olympic and Paralympic sport. Its mission is to work in partnership to lead sport in the UK to world class success.

“Despite having my right leg amputated during treatment, I now travel the world playing wheelchair basketball. I fell in love with the sport when I went along to a roadshow and haven't looked back since! I felt so proud to play for Team GB in the London 2012 Paralympics. Amazing!”  
**Gaz Choudry, 27, diagnosed with bone cancer aged 10**



“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, mother of Ben diagnosed with a spinal cord tumour**

“I ran the Great North Run in between chemo treatments. I felt like a crawled round, but it gave me something positive to focus on while going through chemo.”  
**Gemma, diagnosed with lymphoma aged 24**



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Children's Cancer and Leukaemia Group is a leading children's cancer charity and the UK and Ireland's professional association for those involved in the treatment and care of children with cancer. Each week in the UK and Ireland, more than 30 children are diagnosed with cancer.

We bring together childhood cancer professionals to ensure all children receive the best possible treatment and care. We fund and support research into childhood cancers, and we help young patients and their families with our expert, high quality and award-winning information resources.

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British Medical Association Patient Information  
Awards – Self Care Category Winner 2012



Association of Social Care Communicators –  
Award Winner 2012

If you have any comments on this booklet, please contact us. CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.

