



Children's
Cancer and
Leukaemia
Group

the EXPERTS
in CHILDHOOD
CANCER

Keeping your child active during and after treatment

Practical information for parents about physical activity, sport and exercise for children and young people with cancer



www.cclg.org.uk



About this guide

This booklet is for families of children and young people with cancer. It may also be useful for teachers and those involved in sports clubs. It gives practical advice that may help when thinking about activity levels both during and after treatment.



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Contents

- Why is it important for your child to keep active? 4
- What activities can your child do? 6
- Are you being over-protective? 11
- How can you help and support your child? 12
- How do you start? 14
- Who can support your child? 16
- Practical tips 18
- Useful organisations for help and support 22



“Physical activity and exercise is recognised as one of the most effective ways of improving physical and psychological health and wellbeing for children being treated for cancer and beyond; reducing the impact of some of the side effects of treatment, whilst promoting independence, peer support and self-confidence are all reasons we are passionate about encouraging being active in all forms – walking the dog, visiting the playground, dancing, active gaming and even some yoga!”

**Lucy Waller, Clinical Specialist Physiotherapist,
Great Ormond Street Hospital, London**

Why is it important for your child 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, clubs or something as simple as riding a bike or kicking a ball about with friends.

The treatment for cancer can be very demanding physically. Chemotherapy can have side effects such as pain, fatigue, muscle weakness and muscle tightness. Certain drugs can affect the peripheral nerves causing loss of movement or sensation in hands and feet which may lead to difficulties with balance. Some tumours and surgery may affect balance and coordination. Steroid drugs may cause weight gain which may lead to difficulties with body self-perception and confidence. 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.

Keeping active can help your child to:

- stay fit and well during treatment
- improve their physical function and energy levels for taking part in everyday activities, like climbing the stairs, going to school or playing with friends
- improve their sense of wellbeing and self-confidence through the release of endorphins (feel-good hormones) from exercise
- keep at a healthy weight
- feel they belong, particularly with team sports
- maintain bone density
- relieve constipation
- improve sleep patterns
- develop their physical, cognitive and social skills



“Eden had been cheerleading since she was 2, so when she was diagnosed at 3 years they offered for her to attend classes in lieu of physio to keep her active in a sport she loved. She was never afraid to stunt - wiggly bag and all! (Even though it made my heart jump a few times!).”

Kate, mum of Eden who was diagnosed with ALL aged three

“Amelia has never let her treatment or amputation get in the way of challenging herself and being active. She was determined to dance again and told me: you should never give up on your dreams, if you keep trying you can do anything.”

Michelle, mum of Amelia who was diagnosed with osteosarcoma aged seven



“Despite having my 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 am proud to have played for Team GB in three Paralympics. Amazing!”

Gaz who was diagnosed with bone cancer aged 10

What activities can your 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 activity in question.

What if your child has had surgery?

Physical activity is a really important part of recovery following surgery and instructions will be given specific to your child's situation. Following surgery for a brain tumour, your child may be unable to participate in contact sports. After surgery for a bone tumour in the leg, there may be restrictions on how much weight your child can put on their leg and how much they can move their joints.

In many cases, restrictions won't be permanent and your child's medical team will advise you about when and how you can build this activity back up.

Can your child go swimming?

If your child has a central line fitted, they are advised not to go swimming because of the risk of infection if it gets wet. However, it may be possible for your child to swim wearing a good fitting drysuit designed for children with a central line. Check with your child's team for advice.

If your child is a keen swimmer, having a 'port' rather than a 'line' might be possible so that your child can continue swimming. Your child's medical team will explain the differences between the two and why one might be better than the other. If your child has a 'port', there may still be times when they are advised not to swim, such as low blood counts or feeling unwell. The advice is to only swim in properly chlorinated pools with filters and not to swim in ponds, rivers, the sea or any other open water or unfiltered private pool.

Can your child take part in contact sports?

Contact sports such as football, rugby or martial arts which may involve players grabbing at loose clothing, barging into each other and knocking each other to the ground, are usually not advised if your child has a central line fitted 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 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 your child take part in?

Your child's medical team can give advice about how to participate safely in games and activities. 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. They don't have to be sports related and there are many ways of being active.

Going for a family bike ride or walk, going to a park, playing hide and seek, skittles and hula hoops, going on a treasure hunt, playing dance games with friends and walking the dog are all ways to be active and are things that children can enjoy.



What about PE and non-contact sports?

These can include activities such as tennis, cricket, athletics, horse riding, gymnastics or console-based physical games. Check with your child's surgical team about how long to wait after an operation before doing these. If your child has had brain surgery, you may need specific advice about what your child will be able to do after their operation. If platelets are low, avoid any sport where they may fall, or be struck by the ball, equipment or players.

If your child is immunosuppressed, avoid animal stables, straw and 'mucking out' where they may be exposed to fungal spores.

Can your child go to soft play centres and outdoor playgrounds?

Normal play should be fine, although be cautious if your child has low platelet counts or is immunosuppressed.

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 an important part of their rehabilitation for their general health and wellbeing. Your child's medical team will discuss this with you and give you advice.

How to build small amounts of physical activity into your child's day

- use the stairs instead of the lift when visiting the hospital
- encourage your child to push their wheelchair until they need it
- ask your child to get their own drink from the kitchen rather than asking you
- spend time out of bed when in hospital





“Going outside in the fresh air was always important for us whenever Phoebe was well enough during her treatment. Simple things like playing with bubbles in the garden or a walk around the local park were things that we could do easily. Being all together, especially with her sister, would encourage Phoebe to join in and play.”

Naomi, mum of Phoebe who was diagnosed with neuroblastoma aged nine months

“Eden kept going to forest school throughout her treatment for ALL as she loves being outside. It also made me more comfortable knowing she was safer outside when neutropenic but still able to join in.”

Kate, mum of Eden who was diagnosed with ALL aged three



“Rose was very keen to stay active both during and after treatment. We were able to get a bike for her and her brother from Cyclist Fighting Cancer and she rode it every day as well as taking part in sporting activities at school. Rose now runs for a club and recently came second in the Cross Country Championships.”

Emily, mum of Rosie who was diagnosed with ALL aged five



Are you being over-protective?

Following a diagnosis of cancer, parents may feel overly anxious about their child taking part in sports which could lead to injury, or increased risk of infection.

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.

Some parents are keen for their child to carry on with normal activities and may not be aware of precautions needed to reflect their changed circumstances.

Keeping a balanced view is recommended. There will be days when your child may feel more or less able to do sport or exercise. It is best to encourage them when they can, and support them when they can't. If sport and exercise was something the whole family used to do together such as cycling or walking trips, there is no reason why this can't continue, even with some adaptation.

If you are in any doubt about whether or not your child should take part in sport and exercise, then do discuss it with your child's medical team. There may be occasions, for example, when your child is at high risk of infection and when contact with other children may need to be avoided. Some of these issues are covered in the 'Practical tips' section on pages 18-21.

How can you help and support your 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 while all of their friends can.

It is important that you, and your child, follow the advice of the medical team. They 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, 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 by encouraging your child's friends to update them on team progress and make them still feel a part of it.

Watching sport from the sidelines, without necessarily playing, is a good way to keep in touch, both with the game and with team-mates. It may be possible for your child to get involved with organising and refereeing games.

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 your child's medical team.

As well as encouraging your child to return to activities they may have previously enjoyed, it is worth remembering 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, and the influence of their peers can be important as well as self-consciousness during puberty. It is easy to assume all decisions are cancer-related, but this may not necessarily be the case.

“Whenever we had free time from the hospital and Cohen had the energy we would head outside, straight to the park on his scooter. Even a short time after surgery to his calf he was out on his scooter. It is so important to get time outside doing what kids love doing.”

Kat, mum of Cohen who was diagnosed with rhabdomyosarcoma aged four



“Amelia was dancing on her crutches two weeks after her amputation, playing sports in her wheelchair and dancing in a show two weeks after having her first prosthetic leg.”

Michelle, mum of Amelia who was diagnosed with osteosarcoma aged seven

How do you start?

Having goals to aim for as your child goes through treatment, and afterwards, is important. The best way to start is to set personal goals and achievable targets, even if the goals and targets are very different to ones you might have originally thought of before diagnosis.

While it is important to have a final goal in mind, and to know how the bigger picture looks, it is good to break it down into bite-sized goals, which are more likely to be achievable. Goals do not have to be about climbing the highest mountain, doing the longest walk, or the fastest swim – it may be about just taking the first steps again.

Goal posts can shift, sometimes as a result of treatment or other cancer-related issues, and sometimes because of dips along the journey, which may be totally unrelated to the cancer. It may sometimes feel like two steps forward, and one step back. A step back is not a failure. If it does happen, you can still focus on the end goal, but also look back at the progress that your child has achieved already.

By setting realistic and achievable goals, the whole family can work together. It may help to write your goals down so you can see the progress your child is making, regardless of how big or small the goal is.

Your child's medical team can help you to start setting goals and you can also read the example on page 15.

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

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

Who can support your child?

Physiotherapists are an important member of your child's hospital team who help children on treatment stay as active as possible. Cancer treatment can be 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, including 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 for your child to do at home. They will offer advice and education about re-integration into sport and to help your child exercise safely.

Extreme tiredness (fatigue) can affect most children with cancer and can stop children 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 tiredness.

Your child's hospital team may have details of local organisations 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 support daily routines to manage fatigue. They can modify activities to help your child take part in the things they want to do and to return to play, leisure and sport.

Brothers and sisters can play an important part by encouraging their sibling to join in, for example, kicking a football about in the garden or going on a bike ride.

School friends, 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 only playing part of a game or needing some 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. 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 participation 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 that offer coaching and sport facilities, so please search online for your area.

For more information, please see page 23.



Practical tips

The following practical tips are very general. You will be given specific advice on what your child can do.

This will vary significantly depending on the nature of their diagnosis, type of treatment given, timing, and 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.

LIFESTYLE & NUTRITION

- Make sure your child takes reasonable precautions to **cover up in the sun.**
- Check 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.
- Check your child **drinks enough while exercising.**
- Make sure your **child's calorie intake is appropriate** for their level of activity.



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 distance away from school, after a while, drop your child off so they can have a little walk, gradually extending the distance of the walk over time. Alternatively, going part of the way on a bike or scooter may be easier to start with if walking a long distance is difficult.
- **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.
- **If your child has a central line**, you should ask for specific advice, 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 walk. Discuss pacing activities – the physiotherapist can offer advice with this.

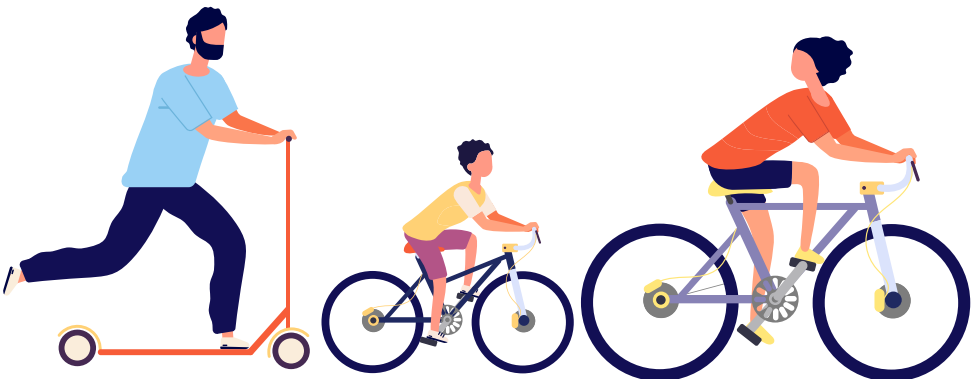
HEALTH

- **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. Your child's team will give you more advice specific to your child's situation.
- **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.** 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. Your child's 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.

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 cancer, 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 late effects or their impact** (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 organisations for help and support

Activity holidays

There are a number of organisations that offer 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 and may provide the opportunity to try new physical activities. They also allow a child to push boundaries, build confidence, work and play together, spend time outdoors, give a sense of achievement and, above all, have fun.

Barretstown

www.barretstown.org

Specially-designed camps that provide therapeutic recreation for children with serious illnesses, and their families.

Climbing Out

www.climbingout.org.uk

Runs residential outdoor activity programmes.

Ellen MacArthur Trust

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

Provides residential camps for children with health challenges and disabilities.

Youth Cancer Trust

www.youthcancertrust.org

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

Other useful resources:

Access Sport

www.accesssport.org.uk/Pages/Category/inclusive-activities

Online activities to do at home.

Activity Alliance

www.activityalliance.org.uk

Supports disabled people in sport and activities.

Back up

www.backuptrust.org.uk

Helps people and their families adjust, rebuild independence and get the most out of life after spinal cord injury.

British Blind Sport

www.britishblindsport.org.uk

Helps blind and partially-sighted people to get active and play sport.

CFC - Helping kids with cancer

www.cyclistsfc.org.uk

Awards bikes to children and young people affected by cancer.

Cosmic Kids Yoga

www.cosmickids.com

Fun interactive yoga adventures for kids.

GoNoodle

www.gonoodle.com

Music and movement videos for kids.

LimbPower

www.limbpower.com

Helps bone tumour and amputation patients with physical activities, sports and the arts.

MOVE Charity

www.movecharity.org

Supports children & young people living with cancer through the power of exercise and sport.

NHS

www.nhs.uk/live-well/exercise/physical-activity-guidelines-children-and-young-people

www.nhs.uk/healthier-families/activities

Fun activity ideas for kids including Disney, Pixar and Marvel inspired 10-minute games.

Transplant Sport UK

www.transplantsport.org.uk

Promotes active recovery for transplant recipients.



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Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

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

Our work is funded by donations. If you would like to help, text '**CCLG**' to **70300** to donate **£3**. You may be charged for one text message at your network's standard or charity rate. CCLG (registered charity numbers 1182637 and SC049948) will receive 100% of your donation.

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British Medical Association
Patient Information Awards –
Self Care Category Winner



Association of Social
Care Communicators –
Award Winner

