

**YOUNG LIVES**  
**vs CANCER**

My child has cancer

# WHAT NOW?

A guide for parents and carers



[younglivesvscancer.org.uk](http://younglivesvscancer.org.uk)

# The new normal

When your child is diagnosed with cancer, it propels you into a new world. Parents talk about switching to 'survival mode' and just trying to get through it. Whether you're staying in the hospital or holding it together at home, it's not easy. But the challenges you face each day are made easier with the right advice and support. That's where we come in.

## Help is here

This booklet should help you to make sense of this new, unfamiliar territory and offer you some next steps. There are no perfect answers and everyone deals with things differently. But at least we can tell you some of the ways your child's cancer diagnosis is likely to affect you and your family, and who you can go to for help – you'll find there is plenty available.

## Someone to talk to

There will be a lot of new things to process and you may still have questions you'd like to talk through after reading the information in this booklet. If you need to talk to someone, our social work team is ready to support you. You may already have a Young Lives vs Cancer team you can talk to. If not, message us online via Live Chat or call our team from Monday to Friday 10am to 4pm. Or you can drop us an email and we'll get back to you asap.

**Live Chat:** go to [younglivesvscancer.org.uk](https://www.younglivesvscancer.org.uk) and click **Chat to us** (bottom right of the page)

**Call:** 0300 303 5220

**Email:** [getsupport@younglivesvscancer.org.uk](mailto:getsupport@younglivesvscancer.org.uk)

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A young boy with curly brown hair and glasses is looking off to the side with a thoughtful expression. A woman's hand is resting on his shoulder, suggesting support. The background is softly blurred.

# DEALING WITH THE DIAGNOSIS

One minute life is carrying on as usual. The next your child is diagnosed with cancer. We know that hearing the word 'cancer' can make the world drop from beneath your feet. We're here to help you navigate the new normal.

# MAKING SENSE OF IT ALL

We understand that this can be a devastatingly difficult time. You may still be feeling shocked or still be struggling to take in the news. Some parents talk about everything being a blur to begin with. They talk about feeling swamped with information and yet unable to take any of it in.

**This booklet is intended to guide you through the first few days and weeks.**

At Young Lives vs Cancer, we're here to help you and your family face whatever cancer throws at you. In this booklet, you'll find more information on the support we provide to keep families going, including free places to stay near hospitals, financial support to help with cancer costs, and practical and emotional support from our social work teams.

## **A handy reference**

If you come across any words or phrases you're not familiar with (in this booklet or at the hospital), make sure you check the glossary at the back of this booklet. We've written explanations for common cancer terms you might hear after your child's diagnosis.

# OUR SOCIAL WORK TEAMS

**Our social work teams are there to support your family with the impact of your child's cancer diagnosis. They deliver a blend of in-person, online and phone-based support. You may have one or the other, or a mix of both depending on your needs. They'll be there to support you throughout your journey and can help in the following ways:**

- From the day the doctor says cancer, Young Lives vs Cancer social work teams will provide exceptional care and support, tailored to each young cancer patient and their family.
- Having a child diagnosed with cancer is traumatic and can be all-consuming. We are here to provide practical, financial and emotional support so you can focus on your child.
- Wherever you live in the UK, and wherever your child is treated, we will be here to support you. If you need to travel for your child's treatment, our team may be able to arrange free accommodation in one of our Homes from Home.
- We will help you navigate the different systems – from applying for benefits to liaising with your employer and your child's school.
- Some support we'll deliver directly but we'll also put you in touch with other organisations or agencies that can help.
- We are independent of all other providers of a young cancer patient's treatment but will work in partnership with them to ensure each child or young person receives the best possible treatment, care and support. We rely on voluntary donations to fund our work, and give all of our support to families for free.





### Your social work team

If you're reading this booklet, it's likely you've got a Young Lives vs Cancer social work team supporting you, who you can speak to. If not – or you're not sure – and you would like our support, please contact us via any of the details on page 2.

# FINDING THE RIGHT INFO

**It's normal to want to jump online and google your child's condition to find out more about the diagnosis and get a clearer picture of what's ahead. But it's important to remember that it's not always the best way to find the answers you need.**

## Why information is important

Many families tell us that information is crucial after their child is diagnosed. Wanting to understand as much as you can is natural, and it can be helpful to know what to expect and prepare for whatever lies ahead. But it's not always easy to take in what medical professionals tell you, especially while you're still getting your head around the diagnosis. That's why it's vital that parents are able to access trustworthy information when it's right for them.

## Searching online

If you type the name of your child's cancer into a search engine you will get a long list of results. This can be daunting. Where do you start? Which websites can you trust? It's important to remember that different cancers affect different people in different ways. It's almost impossible to predict what course your child's cancer will take, no matter how much internet research you do.

If you are feeling confused, try going back to your child's consultant, registrar or nurse and asking them to explain things again. Make a note of any specific questions you have. They are the people who are best placed to help you make sense of things.



## When online, remember:

- Numbers and statistics are open to interpretation.
- Be aware you are more likely to remember negative things than positive ones.
- Claims of miracle cures may not be backed up by proper research.
- Treatments that cost a lot of money overseas and don't appear to be available in the UK will show their published and peer reviewed research if they're legitimate. Always talk these through with your clinical team in the UK.
- Think first about how you'll feel reading difficult material. You may find it easier to read it with someone you trust rather than alone.

## Useful websites

We recommend these websites for accurate, reliable information about cancer in children:

Young Lives vs Cancer:

[younglivesvscancer.org.uk/my-child-has-cancer](http://younglivesvscancer.org.uk/my-child-has-cancer)

Blood Cancer UK: [bloodcancer.org.uk](http://bloodcancer.org.uk)

Children's Cancer and Leukaemia Group (CCLG): [cclg.org.uk](http://cclg.org.uk)

Cancer Research UK: [cancerresearchuk.org/childrens-cancers](http://cancerresearchuk.org/childrens-cancers)

The Brain Tumour Charity: [thebraintumourcharity.org](http://thebraintumourcharity.org)



# PREPARING FOR WHAT'S AHEAD

Along with your medical team in hospital, your Young Lives vs Cancer social work team is here to help and support you. Don't be afraid to ask for help whenever you need it.



# WHO WILL HELP MY CHILD?

Throughout their treatment, your child will be cared for by a large team of people. This is known as a multi-disciplinary team (MDT). Depending on your child's age, and the type of cancer they have, the team could include:

**Advanced nurse practitioner** – A nurse qualified at an advanced level who does physical examinations and medical history taking. This may include giving higher levels of information (such as scan results), prescribing treatments or medicines, and ordering tests and investigations alongside normal nursing care.

**Anaesthetist and intensivist** – Specialist doctors who manage your child's breathing and specialist medical care if they need an anaesthetic or intensive care.

**Clinical nurse specialist** – A nurse who has specialist cancer nursing skills at an enhanced level.

**Clinical oncologist** – A doctor who specialises in radiotherapy.

**Dietician** – A person trained in nutrition. Cancer treatment often causes taste changes, weight loss or weight gain, and a dietician ensures children remain well-nourished during treatment.

**Healthcare assistant** – A nursing assistant who may help with bathing and hygiene, dressing, feeding, providing meals and drinks, toileting and supporting nurses with work.

**Neuro-oncologist** – A doctor who specialises in brain tumours.

**Nursing associate** – May support registered nurses to prepare the equipment required for chemotherapy and support patients through procedures.

**Oncology pharmacist** – Pharmacists with specialist knowledge about children's cancer medicines, the best formulas to use at home and how to manage side effects.

**Paediatric haematologist** – A doctor who specialises in blood disorders, including leukaemia.

**Paediatric oncologist** – A doctor who treats children with cancer.

**Paediatric oncology outreach nurse specialist** – Provides treatment and support out in the community or liaises with the community team.

**Phlebotomist** – Carries out skin-prick testing and takes blood samples.

**Physiotherapist** – A person trained in physical activity and physical function. Physios may help children in specific situations as well as with general activity, such as recovering their lung function after infections or walking again after surgery.

**Play specialist** – Uses play and activities to teach children more about their treatment and what to expect. They can prepare children for procedures and help children after traumatic events. Many play specialists work alongside the psychology team.

**Radiographer** – Takes X-rays, performs specialised scans and gives radiotherapy treatment.

**Radiologist** – A doctor who interprets X-rays and scans.

**Registered ward nurse or day-care/clinic nurse** – These nurses have undergone further education and training in children's cancer care, such as chemotherapy training, and cancer specific education (also known as paediatric oncology nurses).

**Specialist nurse key worker** – Responsible for the coordination of a child's cancer care within the hospital and after discharge.

**Surgeon** – A doctor who carries out operations.

**Ward or clinic doctor** – Most tests and treatments will be requested by these doctors, and they undertake a daily review of patients and their progress.

# Where we come in

Your Young Lives vs Cancer social work team will make sure you get the support you need, working as part of the NHS team. They're specialists in cancer support and will help you handle the day-to-day challenges that come with your child's cancer diagnosis.

▮ Without the support of Laura, we would have been quite lost because it is a different form of support. It is from somebody who knows and understands what families are going through. I think this is where Young Lives vs Cancer Social Workers come in. ▮





# ADJUSTING TO WARD LIFE

If your child has been admitted to hospital, they are probably staying on a children's cancer ward. These are generally friendly, positive places and staff will offer both you and your child plenty of help and support.

## What's the ward like?

Many parents tell us they found seeing the ward for the first time challenging. Try to remember that the most important things can be hard to see at first – like the caring professionals who will be there by your side throughout, or the chance to form friendships that can provide a new layer of support.

It may also be helpful to know that children usually only stay on the ward when they need inpatient treatment or if they are very unwell. Many children are eventually able to get on with their lives while continuing cancer treatment at home, at an outpatient clinic or during short stays in hospital.

## What about privacy?

It can take a while to get used to sharing space. Feel free to draw the curtain round and spend some quiet time with your child when you need to. Occasionally, you may be asked not to do this if staff want to closely observe your child. Just ask if you aren't sure.

## What are the facilities like?

Most children's wards have staff and facilities to help keep your child occupied – ask a member of staff what's available. Only your child is eligible for hospital meals, but there will usually be a kitchen where you can make a cup of tea and possibly prepare snacks. There are usually showers available for parents and a place to wash your clothes.

# Can we have visitors?

Hospital wards sometimes have regular visiting hours when family and friends are encouraged to visit, although most paediatric wards have open visiting for parents and carers. Check with the staff on the ward about when visiting hours are and if there are any particular rules around visiting, for example the number of visitors your child can have.

There may be additional rules around visiting your child's ward, dependent on the current national health climate. Be sure to check if your ward has any of these extra guidelines.

## Questioning your child's care

If you are unhappy with your child's care or would like to question the reasoning behind a decision, ask to speak to the nurse in charge. Many things can be resolved quickly. If not, ask for an appointment with the ward manager.

If you feel the problem still hasn't been resolved, the hospital will have a support team you can speak to for confidential advice and support:

- Patient Advice and Liaison Service (PALS) in England and Wales.
- Patient Advice and Support Service (PASS) in Scotland.
- Your local health and social care trust's complaints manager in Northern Ireland.

Visit [nhs.uk](https://www.nhs.uk) and search for 'PALS' to find out more.

# What you'll need in hospital

Here are some items that other parents like to keep packed for a hospital stay:

- Toiletries – lip balm, hand cream and moisturisers can be particularly handy.
- Entertainment for your child – whether that's toys, games, activity books, a laptop, tablet or smartphone.
- A long charging cable or powerbank for your phone or tablet.
- Your child's favourite snacks and drinks.
- Books and magazines or anything to keep you occupied.
- Clothes for you and your child.
- Something snugly for your child to wear like pyjamas, slippers and a dressing gown.
- Diary or organiser and a pen to take notes.
- Washing powder or liquid.
- Anything your child will find comforting to have with them such as a cuddly toy or photographs.
- A portable fan as hospital wards can sometimes get quite warm.

## Electrical items

These may need to be tested before you can use them on the ward. Check to see what the rules are for your hospital. If they do need testing, healthcare assistants on the ward can usually organise this for you quite quickly.

# Tips for coping with ward life

- Aim to get off the ward for a short break each day, even if it's just for a quick coffee or a walk around the block. Ward staff will support you with this. When you leave the ward, let a member of staff know how long you'll be gone and how to contact you if necessary.
- Try to keep things as normal as possible for you and your child – that includes the usual boundaries you set for their behaviour.
- If you have any worries or questions, talk to a member of your child's care team. It may be helpful to write down questions as they occur, so you remember them.
- Most children's wards have a TV and video games available, and these can be a useful way for you and your child to build relationships with other families.
- Try taking an active role in your child's care by helping them with meals, wheeling their drip, taking them to the toilet and so on.
- If your child is struggling to cope with aspects of treatment, most children's wards have play specialists who can help. They use play and activities to help children understand what's happening and cope with their treatment.

# WHAT CAN I DO NOW?

In the shock and haze of a diagnosis it can be especially difficult to think about practicalities. But making arrangements and getting your head around things now should help you in the days and weeks ahead. It might be a good idea to read this section with a friend or relative who could lend a hand with some of the logistics.

## Accommodation

Our Homes from Home are a free place for families to stay when their child is going through cancer treatment. They're close to principal treatment centres, helping families avoid the extra financial burdens of travel, accommodation and food costs. Parents, carers and siblings are welcome to stay in our homes, and other family and friends can visit too. The hospital may also have other accommodation nearby.

Chat to your Young Lives vs Cancer social work team about what's available to you.

## Money

Cancer can often bring extra costs with travel for treatment, reduced working hours and childcare arrangements.

Young Lives vs Cancer provides a one-off grant that you can use to cover food, travel or other day-to-day costs. You may also be able to access other grants and certain benefits to help with this.

Talk to your Young Lives vs Cancer social work team about our grant and see page 31 for more information about financial help.



## Travel

Travel to and from your child's hospital, whether by car or public transport, can be expensive. If you are on a low income and receiving benefits, the hospital may reimburse part or all of your travel costs, so remember to keep your receipts. Free hospital transport may be available if your child has clinical needs that make using public transport impossible.

Check with your child's consultant or nurse to confirm whether your child can travel by public transport. They should make you aware of your options.

## Parking

The cost and availability of parking varies from hospital to hospital. You may be able to buy a weekly, monthly or even annual parking permit that works out cheaper. A Blue Badge can also help with parking costs. Your local authority may issue one if your child has mobility problems. If you are eligible to recover hospital travel costs, these can include unavoidable parking charges.

Check the hospital's website for details and ask your Young Lives vs Cancer social work team if any support is available at your child's hospital.

## Childcare

If you have other children who will need looking after while you are at the hospital, finding consistent childcare can be a problem. If you or your partner is employed, you or they may be entitled to time off for dependants in order to organise emergency childcare (see page 39).

In the longer term, it's a good idea to find someone who is willing to look after your other children at short notice if you need to take your child to hospital unexpectedly.

A close-up photograph of a man with a beard and glasses kissing a young boy on the cheek. The man's eyes are closed, and the boy is looking towards the camera with a slight smile. The background is dark.

# TALKING TO PEOPLE

Talking to people about your child's cancer diagnosis can be daunting, especially if you haven't yet got your head around it yourself. But being honest and straightforward about your situation will usually be a positive experience – both for your family and others close to you.

# TALKING TO YOUR CHILD

Parents tell us that one of their biggest concerns after diagnosis is what to say to their child about their cancer and its treatment. Children all have different levels of understanding and it can be hard to know what information they need and which words to use.

## Knowing what to say

If you aren't sure what to say, or how to say it, start by taking a look at one of our storybooks for children about cancer. They will give you an idea of the words to use and how things can be explained simply and clearly. See more on page 46.

While it's not possible to talk to babies and toddlers about what's happening, your calming, reassuring presence is vital, particularly during medical procedures.

## Tips for talking to your child

- Keep it simple and do it gradually – you may need to repeat all or part of what you say several times.
- Be as honest as you can.
- Ask if there is anything they are worried about.
- Don't feel you have to have all the answers.
- It's fine if they don't want to talk. Just reassure them that you'll be there when they are ready.
- Remember to revisit conversations as your child gets older.

# BROTHERS AND SISTERS

Siblings may be feeling worried, left out, thrown by the change in routine or simply missing your attention. Parents often worry that telling a sibling their brother or sister has cancer will upset them too much or that they're too young to understand. But children are very good at picking up when something 'big' is going on.

## How they might be feeling

They might worry that they have somehow caused the cancer and younger children may also worry about 'catching' cancer. It can be tough when your other children look to you for reassurance when you have your own worries, but it's important to talk to them openly and honestly so they don't imagine the worst.

## Tips for talking to siblings

- Children's storybooks about cancer are a useful way to start a conversation (see page 46).
- It's fine if children don't want to talk – just let them know that you are happy to do so when they feel able to.
- Let them know that sharing worries with other people often makes things easier.
- Keep schools up to date with what is happening.
- Asking questions that aren't about your child's illness, like "What's going on with you at the moment?" will let siblings know you're thinking of their feelings too.
- Some hospitals or local charities have support groups for siblings. Your child's medical team or Young Lives vs Cancer social work team will have more information about these. They may be able to access other support services for siblings like counselling.

# Change in routine for siblings

When a child receives a diagnosis, family routines change and siblings can find this particularly challenging. There may be a change at school or nursery, less contact with friends and family or an unexpected break from usual hobbies or activities taking place outside of the home. It's also common for siblings to struggle with changes in routines that come with things like appointments and hospital stays. Here are a few things that might help:

- Talk about what is going to happen and when. Mark the dates on a calendar – talk about what routines will be in place for them when you are away and who will help to look after them.
- Ask if there are any things that are particularly important at that time – things at school or a friend's party. Reassure them that they can still do these things and that the person who's looking after them while you're away will be told they are important and will make sure they happen.
- Even young children like to know what's happening to their brother or sister while they're in hospital. Do a drawing to explain where they need treatment, explain about why this appointment or scan is important for their sibling and talk about some of the things that may happen in hospital. Include normal everyday procedures as well, such as having food or playing with a toy, so that familiar things are included.
- If your child has to go into hospital for treatment, ask the hospital play staff to help support your other child/children too. They may be able to do this themselves or may know of other local organisations who can.
- Try and build in some one-to-one time, and where possible between the children too. Book in time when you can just spend time together, maybe bake a cake or just watch a film together one-to-one. Siblings could play a virtual game together or one could read the other a book to stay connected while they're apart.

- When you are away at the hospital, ask them to draw or write things to bring when they visit. Get someone else to keep a diary of all they have been doing so that you can talk about these everyday things together. They need to feel that these 'normal' things are still important to you. This will also keep everybody involved in these everyday conversations and help ease back into the routine once you are all at home together again.
- You can find more information on supporting siblings on our website: [younglivesvs cancer.org.uk/siblings](https://www.younglivesvs cancer.org.uk/siblings)
- You might also find it helpful to contact Sibs, a charity that supports children whose siblings have a disability: [sibs.org.uk](https://www.sibs.org.uk)



# TELLING OTHER PEOPLE

Lots of parents say how difficult they find telling friends and relatives that their child has cancer. And yet the people closest to you can be a huge source of strength to your family at this difficult time and throughout your child's cancer treatment. Although it can be daunting, telling others may help you to make sense of the situation yourself and feel more in control.

## When telling others about your child's diagnosis:

- Start by thinking about who needs to know, and then who you need to speak to personally.
- Don't feel you need to tell everyone everything at once.
- Is there someone you can ask to let others know on your behalf?
- You may find it easier to break the news over the phone or on social media.
- Start by saying something like: "I'm afraid I've got some worrying news..."
- Tell your friend or relative what's happening a few sentences at a time – like you, they won't be able to take in too much in one go.
- Try not to be upset if they don't seem to know what to say – this is very normal to begin with.

# How people can help

Friends, colleagues and family members are bound to ask you if there's anything they can do to help. But it can be difficult to think of an answer, especially in the midst of what's going on. Try to think about practical tasks, like collecting the other children from school. Being specific makes it easier to plan and could give you a few less things to think about.

Our website suggests ways people can help make life a little easier at this difficult time. Just ask friends, family and colleagues to visit [younglivesvs cancer.org.uk](https://www.younglivesvs cancer.org.uk) and search 'how to help'.

## Online support groups

Some parents feel they benefit from talking to people with similar experiences. At their best, forums can provide moral support and comfort, making you feel less alone or isolated. However, be cautious of posts about 'miracle cures' or alternative treatments, especially if you are being encouraged to buy specific products. Also be aware of discussions which are highly negative or not suitably monitored by moderators.

### **Our Facebook groups for parents**

Young Lives vs Cancer has a Facebook group for parents and carers, and a 'Mind the Chaps' Facebook group just for dads. To join, search 'Young Lives vs Cancer for parents and carers' or 'Mind the Chaps' on Facebook.

# TALKING TO YOUR PARTNER

Your life and your partner's life will have changed dramatically since your child's diagnosis and you're probably both experiencing a number of different emotions and stress. Understandably, this might have an effect on your relationship. There will be little time for those things that strengthened your relationship before diagnosis (like date nights and family trips) as you are pulled in different directions between your ill child, their siblings, hospital, work and home.

## Our tips for looking after your relationship are:

- Be clear on your responsibilities. Many couples, co-parents and step-parents can find themselves changing roles within their relationship, parenting or family set-up. This can cause additional stress as you may have to do things you haven't done before. Make sure roles and responsibilities for your child and your family are clear and openly discussed regularly as things change.
- Communicate and stay honest and clear with each other about how you're feeling, as this can help make sure you're both on the same page.
- It can be difficult to find a spare minute or two, but if you can, try to make some time just for you and your partner to reconnect. A quick cup of tea together still counts.
- Remember you're a team. It might seem like you're living different lives – one of you might be working while the other is at home or in hospital looking after your child – but you'll have the same worries. Remember you're on the same side and that you're not alone.
- If things get really tough, there are some organisations who can support couples. Ask your Young Lives vs Cancer social work team or your clinical nurse specialist if the hospital has couples' counselling, or check out Relate ([relate.org.uk](https://www.relate.org.uk)), the UK's leading relationship support organisation.



# KEEPING ON TOP OF THINGS

With everything else going on, it can be a challenge to stay afloat with money, work and your child's education. Remember that help is always available from your Young Lives vs Cancer social work team. Keep talking to people and make sure you're getting the support you need.

# WHAT ABOUT MONEY?

You will almost certainly have extra costs while your child is being treated for cancer. We know parents find this a worry, especially if you also have to reduce your working hours to care for your child. But financial help is available in the form of benefits, allowances and grants, some of which are listed on the next page.

## Accessing benefits

Claiming benefits and allowances involves filling in lots of forms. Parents often say they simply can't cope with this in the early weeks after their child is diagnosed. At the same time, it's important to claim as soon as possible because some payments can't be backdated.

## Who can help?

Your Young Lives vs Cancer social work team can help you with applying for benefits. For free specialist advice or a review of what you're entitled to, contact our Welfare Advice Service on **0800 915 4439** or [welfare.advice@younglivesvscancer.org.uk](mailto:welfare.advice@younglivesvscancer.org.uk), available on Tuesday, Thursday and Friday between 10am and 4pm.

# What benefits are available?

Understanding the benefits system isn't always easy, but it can help you cope during difficult times. There are a range of different benefits that could help take the pressure off.

## Universal Credit

This is a monthly means-tested benefit for people who are on a low income, as long as their savings and other capital (excluding the value of their home) are worth no more than £16,000. Universal Credit must be claimed by both members of a couple, so each partner's income and capital is taken into account. The amount you're entitled to also depends on who is in your household, and additional amounts are available if a child receives a disability benefit such as DLA (Disability Living Allowance) and/or PIP (Personal Independence Payment).

## Disability Living Allowance (DLA)

This is a (non-means-tested) benefit for children under 16 who have a serious illness or disability. The amount you can receive depends on the level of care your child needs and/or on any mobility problems they have. An award of DLA can mean that a family gets additional entitlements such as Carer's Allowance or a Blue Badge, as well as additional entitlements under means-tested benefits such as Universal Credit and Child Tax Credit. DLA can only start when your child has met the health criteria for three months, but you can apply before the three months have elapsed. In Scotland, DLA has been replaced by Child Disability Payment. You can read more information about DLA and Child Disability Payment on our website:

[younglivesvcancer.org.uk/dla](http://younglivesvcancer.org.uk/dla)

## **NHS Low Income Scheme (LIS)**

If you have a low income, you may be able to get help with NHS costs, such as the cost of travelling to and from hospital appointments, through the NHS Low Income Scheme (LIS). Depending on your circumstances, you can receive full help or partial help. You can apply online or via post by completing an HC1 form. If you receive certain benefits you qualify automatically and don't need to submit the HC1 form.

## **Personal Independence Payment (PIP)**

PIP has replaced DLA for people aged 16 or over. Like DLA, PIP is a non-means-tested benefit, and is assessed on a points-based system that aims to measure your ability to carry out activities such as cooking, bathing and moving around. The PIP applicant must be likely to continue to meet the criteria for a further nine months after PIP is awarded. In Scotland, PIP has been replaced by Adult Disability Payment. For more information about PIP and Adult Disability Payment, visit our website: [younglivesvscancer.org.uk/pip](https://www.younglivesvscancer.org.uk/pip)

Depending on your circumstances, you may also be eligible for further support such as:

- Carer's Allowance
- Working Tax Credit
- Housing Benefit
- Council Tax Reduction



# Tackling day-to-day expenses

We know that the financial pressures of paying for day-to-day living expenses on top of additional costs relating to your child's cancer treatment may be a struggle. However, there may be ways that you could reduce your expenses.

## Travel expenses

If you're on a low income your child's hospital may help with certain travel costs when you travel with your child. You could also receive parking concessions.

## Utility bills

Most energy providers offer income-based grants to clear gas or electricity arrears or help with other household costs. You may also be entitled to help with water charges. Water companies and many broadband suppliers also offer cheaper 'social tariffs' to people on low incomes. Ask your local Citizens Advice or an independent debt adviser such as StepChange or National Debtline, who may be able to help you apply for assistance.

## Mortgage

Let your bank know about your child's diagnosis – some banks have dedicated support teams for those impacted by cancer. Check with your mortgage provider whether you have payment protection on your mortgage and if you qualify now that your child is ill. It may also be possible to get help with your mortgage costs if you claim certain benefits, but the conditions for this help are very difficult to meet.

## Life insurance

Your life insurance policy may include serious illness cover and, if so, this could cover your children.

## Motability Scheme

Depending on your circumstances, this scheme could help you with the cost of buying, leasing or adapting a car.

Visit [motability.co.uk](https://www.motability.co.uk) for more information.

# Grants

Young Lives vs Cancer offers a grant to all families who have a child with cancer, to help with the immediate costs after diagnosis. You may also be eligible to receive other grants.

█ The grants provided by Young Lives vs Cancer are a lifeline. I had to stop working to look after Patrick. If we weren't getting the money we are from the grants I don't know what we would do. Lucy was so brilliant, she showed us how to fill out all the awful forms we were faced with and she was the only person that offered us any help with things like that. █

## More information

You can find further information to help you manage your finances and understand benefits at [younglivesvscancer.org.uk/help-with-money](https://younglivesvscancer.org.uk/help-with-money). For the most up-to-date information about government benefits and support visit [gov.uk](https://gov.uk), [mygov.scot/browse/benefits](https://mygov.scot/browse/benefits) (Scotland) or [nidirect.gov.uk](https://nidirect.gov.uk) (Northern Ireland).

# WHAT ABOUT SCHOOL?

**Getting your child well again is bound to be your main priority at the moment. However, your child may be having treatment for some time, and it's important that their education continues.**

## Why it's important

This isn't just so that your child can keep up with their curriculum. Lots of parents find that schoolwork helps to give their child some much-needed structure and consistency while they go through treatment, as well as building their confidence about coping with the return to school.

## Contacting the school

Initially you, or a trusted friend or relative, will need to phone your child's headteacher to let them know about their diagnosis. Your Young Lives vs Cancer social work team may be able to do this if you prefer. They can also help you liaise with the school and keep them up-to-date with what's happening.

## Home education

If your child is of compulsory school age, they will be entitled to education at home if they are out of hospital, but not well enough to return to school full-time. Schools will vary in how they approach this and how education is given, but your Young Lives vs Cancer social work team can liaise with the school and help you ensure that education continues during this time.

## Hospital school

Most children's cancer hospitals have education departments, or schools, that can support your child while they are in hospital. The hospital teachers can contact your child's school to make a plan and set work that allows your child to carry on learning whenever they are well enough. The child can even take exams in hospital or at home if necessary, and special consideration is given by the exam boards if exams are during treatment.

## Staying in touch with friends

The friends your child has at school are very important to them. Encourage your child to stay in touch with them via cards, letters, texts, emails, phone calls, video calls or social media. Your child's hospital teachers can support you with this or visits from school friends too if your child is well enough.

### A free learning pack for teachers

Our 'Cancer and school life' pack should help schools feel equipped and confident in ensuring a pupil with cancer and their family has a positive experience and support. Find out more on page 46.

## Top tips for managing education

- Ask your child what, if any, information they would like to share with their classmates and teachers at school.
- Ask to meet with your child's school so you can discuss with them what they can do to help.
- Provided they feel able, encourage your child to do as much schoolwork as they can each day.
- Once they are well enough, encourage your child to attend school as much as they can, even if it's just for a short time each day.
- Your Young Lives vs Cancer social work team may be able to speak to their class before they return. They can also help your child to settle back into school.
- Make sure a trusted member of staff is always available for your child to talk to if any issues come up, and that your child knows who to go to.
- Ask your child's school friends to help support your child when they return. Depending on the age of your child, a teacher may be able to help with this.

## Going back to school

If your child's health and treatment allow, they may be able to go back to school. This could be part-time to begin with. Some children welcome the chance to get back to school and to see their friends.

Others, particularly teenagers, may feel more anxiety about going back. This could be because of changes in their appearance or worries about relationships with their peers. Some cancer treatments may affect a child's ability to learn and this can affect their confidence too.

The school might choose to write an Individual Healthcare Plan for your child, which sets out exactly what care will be needed in school and who will give it. This should be supportive and helpful, showing you that the school is thoughtful about your child's needs in school. Parents, carers and medical staff should be included in the writing of the plan.

Children with cancer automatically meet the definition of 'disabled' under the Equality Act (England, Wales and Scotland) and the Disability Discrimination Act (Northern Ireland). Education and training providers have a duty not to discriminate against potential, current or former students. If you feel like your child's school is not supporting your child on their return to education, seek support from your Young Lives vs Cancer social work team or visit [contact.org.uk](https://www.contact.org.uk)

■ Although learning was a struggle, going to school helped her develop social skills again and have a daily routine. ■

# WHAT ABOUT WORK?

If you work, you may have already phoned your employer to tell them about your child's diagnosis. You can also ask your Young Lives vs Cancer social work team for support with this. If you are able to, let your employer know roughly how long you will be away.

## Managing work

You may also be wondering how you are going to manage work in the long term. The truth is, it probably won't be easy. While work can give valuable structure to your life as you support your child through treatment, there may be times when it's simply not possible. In this case, if you are an employee, you have certain rights. You may be entitled to take some unpaid leave and also to work flexibly.

## Time off for dependants

If you are an employee, you have the right to unpaid time off work to deal with emergencies involving a dependant, such as an unexpected or sudden crisis. This time off can be used to deal with the immediate problem or plan how to handle it, but it can't be used for long-term care. How much time off you can take will depend on your situation.

## Parental leave

All parents are entitled to 18 weeks of parental leave. It is normally unpaid and available for each child up to their 18th birthday. You will need to have worked for the organisation for at least one year. This scheme is different to the Shared Parental Leave entitlement for parents.

## Flexible working

Anyone can ask their employer to work flexibly, but if you have worked for your employer continuously for 26 weeks you have a statutory right to ask for flexible working. You could ask to work from home, for example, or to work flexi-hours or part-time.

The government has proposed new legislation that would mean workers could ask for flexible working from day one. Check the government website or Acas for the most up-to-date guidance.

### **Discrimination at work**

In England, Scotland and Wales, parents and other carers of children with cancer are protected from direct discrimination and harassment at work by the Equality Act (2010). This means, for example, that if you are treated differently from another employee because you are the parent of a child with cancer (for instance, if you are treated differently because you've taken time off work to care for your child), you are protected by this legislation. In Northern Ireland parents are protected under the Disability Discrimination Act, while different legislation applies to carers. For more information visit: [nidirect.gov.uk/articles/overview-carers-rights](https://www.nidirect.gov.uk/articles/overview-carers-rights)

### **Speaking to your GP**

If dealing with your child's illness becomes too stressful and you are struggling at work, you could speak to your GP. They may suggest the option of a 'fit note'. For the most up-to-date information about employment rights, visit [gov.uk](https://www.gov.uk) or [nidirect.gov.uk](https://www.nidirect.gov.uk).

### **Get more support**

Acas offers free, impartial advice on workplace rights. For more info visit [acas.org.uk](https://www.acas.org.uk)







# LOOKING TO THE FUTURE

Supporting your child through cancer treatment can be a lengthy and draining process but remember that help is always at hand.

It's made us realise that life is for living and we're not going to sweat the small stuff.

# HELPFUL SUGGESTIONS

- Make sure you tackle any financial, employment or housing difficulties as they come up – if you delay they may only get worse.
- Make good use of any offers of help, but take care not to let other people start 'organising' you.
- Seek out support, whether it's from staff at the hospital, other parents, friends, relatives or through online groups.
- Try to give all of your children clear boundaries and a normal level of discipline, including your child who is ill.
- Don't neglect your own needs – try to eat well, get plenty of sleep and take some exercise. Even a walk outside the hospital could help you feel better.
- Try not to bottle up your feelings – talk to your partner, friends and relatives as openly and honestly as you can. If you feel you need it, ask your child's care team whether professional counselling is available.
- Caring for a child with cancer is hard on friendships, and you may find that some friendships do not last the course. However, many families also make new friendships and are shown kindness, help and support, sometimes from unexpected places. Keeping up at least some of your usual social activities can give you a welcome distraction during this difficult time.





# EXTRA SUPPORT

We hope this booklet will act as a good starting point but here are some other ways we can help you, as well as additional sources of support.

- They helped us keep control of the little things when we couldn't control the big things. ■

# HOW WE CAN HELP YOU

- Your Young Lives vs Cancer social work team will support you emotionally and help you manage the day-to-day challenges that will come with your child's cancer diagnosis. They'll also provide information and support to your whole family.
- You'll have access to trusted information for children, young people and families, about cancer, its treatment and impact.
- We'll help you in managing the financial impact of cancer. Our welfare advisers will provide information about benefits you're entitled to and your rights so you can make informed decisions.
- We'll help your child continue their education. We can liaise with you and their school to develop the best plan to help them keep up with their studies and stay connected with their friends. We can also help them cope with returning to school.
- We can offer your family a free place to stay together at a Young Lives vs Cancer Home from Home. They offer a comfortable home-like environment close to your child's hospital during their treatment.
- We can help you with your employment. We can talk to your employer about reducing working hours or working flexibly.

For more information, talk to your Young Lives vs Cancer social work team or visit [younglivesvscancer.org.uk](https://www.younglivesvscancer.org.uk)

# OUR RESOURCES

Our free booklets and resources cover a range of different topics. You can download them or order free copies from [younglivesvscancer.org.uk](http://younglivesvscancer.org.uk). Here are some you might find useful:

## Storybooks for children

Our series of illustrated storybooks follows the journeys of four children through diagnosis and treatment. The stories give an honest depiction of cancer and treatment, but also demonstrate how obstacles can be overcome with the right support and the positivity to be found along the way. They are ideal to use with children to help explain what's going on and contain a glossary to explain the technical terms you may come across during hospital stays.

## 'Cancer and school life' pack

It's vital that your child gets support and understanding from their school and classmates during treatment and on their return. Young Lives vs Cancer's 'Cancer and school life' pack is designed to help schools feel equipped and confident in ensuring a pupil with cancer and their family have the best possible experience. The pack provides information and a lesson plan that aims to keep teachers and schoolmates in regular contact and to make your child feel involved and valued.

### **'How can I help?' leaflets**

Although offers of help may be appreciated, sometimes it can be hard to think of what you need after a diagnosis. Give this leaflet to friends, family, colleagues and anyone else who is willing to offer help at this time. It offers tips and guidance on how they can best offer practical and emotional support in the days and weeks ahead.

### **Online information**

We have a huge wealth of information and video content on our website for parents, young people and children. This includes advice on the many ways cancer can affect your life and guidance about how manage the impact, as well as stories from other parents. Go to [younglivesvs cancer.org.uk](https://www.younglivesvs cancer.org.uk) to get started.



# OTHER ORGANISATIONS

Our Young Lives vs Cancer team is always here to answer your questions and offer you as much support as we can. There are also other organisations that can offer you further support and information as and when you need it.

## Action for Sick Children

Advice and information for parents who have children in hospital  
0800 0744 519 (freephone) [actionforsickchildren.org](http://actionforsickchildren.org)

## Contact

Information and advice service for families with a disabled child  
**0808 808 3555** (freephone) [contact.org.uk](http://contact.org.uk)

## Macmillan Cancer Support

Information and support for anyone affected by cancer  
**0808 8080 000** (freephone) [macmillan.org.uk](http://macmillan.org.uk)

## Teenage Cancer Trust

Support for teenagers and young people with cancer  
**020 7612 0370** [teenagecancertrust.org](http://teenagecancertrust.org)

## Cancer Research UK

Reliable cancer information  
[cancerresearchuk.org](http://cancerresearchuk.org)

## Children's Cancer and Leukaemia Group

Latest information about children and young people's cancers  
[cclg.org.uk](http://cclg.org.uk)

# NOTES

Our doctor is called.....

The diagnosis is called.....

Our ward name is.....

Visiting hours are.....

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# GLOSSARY

**Blue Badge** – Some children and young people with cancer will qualify for a Blue Badge. A Blue Badge allows you to park close to where you need to go, such as in disabled parking spaces. Although the scheme applies throughout the UK, the rules about who qualifies are different in each of the nations. You need to apply by contacting your local authority, and there may be a small administrative charge.

**Carer's Allowance** – Carer's Allowance is the main benefit for carers. If you are looking after someone for 35 hours a week or more, who gets a qualifying disability benefit, you may be eligible.

**CNS** – A clinical nurse specialist (CNS) is a senior nurse who helps link the MDT together (see page 12). CNS is also an abbreviation for central nervous system.

**Consultant** – Consultants are senior doctors that are specialists in a particular area of medicine.

**Counsellor** – Works with clients experiencing a wide range of emotional and psychological difficulties.

**Disability Living Allowance (DLA)** – DLA is a non-means-tested benefit to help with the extra costs of looking after a child who is under 16 years old and has difficulties walking or needs much more looking after than a child of the same age who does not have a disability. See page 32 for more details.

**DS1500 or SR1 form** – A DS1500 or SR1 form describes your child's conditions and treatments, completed by a healthcare professional. This is submitted to the Department for Work and Pensions (DWP) for your child to be fast-tracked to a benefit award and/or being awarded a benefit at a higher rate on the basis that they are terminally ill.

**Education, Health and Care (EHC) plan** – An EHC plan is for a disabled child or young person with special educational needs who requires more help than a mainstream school can offer from its own resources. In Wales this is called a Statement or Individual Development Plan (IDP). In Scotland this is called a coordinated support plan (CSP). In Northern Ireland it is referred to as a Statement of Special Educational Need (Statement).

**Emergency leave** – Employees have the right to unpaid (for some this might be paid) time off work to deal with emergencies involving a dependant. An emergency means an unexpected or sudden crisis. Anything known about in advance, like appointments, do not qualify.

**Flexible working** – Is a way of working that suits an employee's needs, for example having flexible start and finish times, working from home, job sharing or compressed hours. Any employee who has been in their job for 26 weeks or more has the right to ask for flexible working. The employer doesn't have to grant such a request, but must give it reasonable consideration.

**Hospice** – Provision that provides end-of-life care to children and young people and their whole families.

**Individual Health Care Plan (IHCP)** – An IHCP is specifically for children with complex medical needs in school to ensure their medical needs are met by the school. This plan may be called something slightly different depending where you live in the UK.

**Grant** – A grant is money that you do not have to pay back, often awarded for a specific purpose (for example, for education or household bills).

**MDT** – A multi-disciplinary team (MDT) is made up of healthcare professionals. See pages 12-13 for who this may include.

**NHS Low Income Scheme (LIS)** – If you have a low income, you may be able to get help with NHS costs, such as the cost of travelling to and from hospital appointments, through the NHS Low Income Scheme (LIS). See page 33 for more details.

**Paediatric** – Any patient aged 0-16 years old.

**Palliative** – The recognition of non-curable cancer and therefore change of the treatment plan to management rather than recovery.

**Parental leave** – All parents who are employees are entitled to 18 weeks of parental leave for each of their children, if they have worked for their employer for a year. This is normally unpaid, unless you agree otherwise, and is available for each child up to their 18th birthday. An employer cannot be made to grant more than four weeks' parental leave in any year.

**Personal Independence Payment (PIP)** – PIP is a non-means-tested benefit to help with any extra costs that may come with having a health condition or disability. See page 33 for more details.

**Paediatric Oncology Outreach Nurse (POON)** – Nurses who provide a link between home and hospital by providing support, advice and care in the community.

**Paediatric Oncology Shared Care Unit Hospital (POSCU)** – A hospital closer to the family home that can provide some care (for example, antibiotics, blood tests).

**Psychologist** – A trained mental health professional who helps people learn healthy ways to handle mental health challenges.

**Psycho-social meeting** – A meeting to look at the psychological and social aspects of cancer and the treatment plan.

**Principal Treatment Centre (PTC)** – A PTC is a centre where a child will be diagnosed with cancer and the treatment plan decided. Depending where the child lives in the country they may go to the PTC for all of their cancer treatment. In some parts of the country cancer treatment can be given at a shared care hospital.

**Referral** – The act of referring someone for consultation, review or further action (with their consent). Your social worker may refer you to other charities for additional support.

**Relapse** – The return of a disease or the return of signs and symptoms after a period of improvement.

**SENCo** – A Special Educational Needs Coordinator (SENCo) is a teacher or other education professional who helps the teaching and learning of pupils with special educational needs and/or disabilities within their primary or secondary school.

**Signposting** – Directing people to other sources of support and services.

**Social worker** – A trained professional who can help you and your family adjust to life during and after cancer treatment. Social workers can help with a huge range of practical and emotional issues, such as dealing with finances, employment issues or schools.

**Statutory Sick Pay (SSP)** – If an employee is unable to work for health reasons, they are likely to be entitled to Statutory Sick Pay (SSP). This should be paid for up to 28 weeks as long as the employee meets certain criteria. Many employees are entitled to Contractual Sick Pay (CSP) at a higher rate than SSP.

**TYA** – In the UK, Teenage and Young Adult (TYA) services are for young people aged 16 up until their 25th birthday.

**Universal Credit** – Universal Credit is a payment to help with your living costs. It's paid monthly, although people in Scotland and Northern Ireland can choose to be paid twice monthly. You may be able to get Universal Credit if you're on a low income, out of work or you cannot work. See page 32 for more details.





# YOUNG LIVES vs CANCER

This booklet was created in collaboration with parents and carers who have been supported by Young Lives vs Cancer. We would like to thank those who helped us create this resource and who gave their time to help other families facing cancer.

For more information on what we do, go to  
[younglivesvscancer.org.uk](https://www.younglivesvscancer.org.uk)

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