

when cancer doesn't go away

a guide for living with advanced cancer



shine
CANCER SUPPORT



contents

welcome to Shine!	5
dealing with your diagnosis	6
living well	12
relationships	17
getting support	18
sex	19
dating	20
supporting children	21
menopause	22
fertility	24
work - what to do now?	25
accessing palliative care	28
planning ahead	30
tips from the community	34
useful questions	35
notes	36



welcome to Shine!

We've developed this guide for those in our community who call themselves 'Lifers' – those people who are living with cancer that won't go away.

You might refer to it as stage 4, advanced, metastatic, incurable, or something else. You may be on tablets, regular chemotherapy sessions, or you may not be receiving any treatments. We're all different but we all have similar concerns and we wanted to create a booklet that could help at what we know is a really difficult time.

We're here to remind you that having advanced cancer doesn't define you and that you can still have a fulfilling life. We can provide you with information and support to help you deal with your diagnosis, so that you can concentrate on all the great things in your life.

At Shine, we support adults in their 20s, 30s and 40s with a cancer diagnosis – any cancer type, at any stage. We know that you face different issues to older or younger people and we host **programmes, workshops and online support** to help you navigate these. Our activities are all designed to bring people together, share experiences, and help you take back control – in a relaxed environment. Whether you're digging deep into a difficult subject or looking for a trip away, we've got lots of options to suit different lifestyles.

We have an amazing community of young people that are ready to chat, share, and support each other, so you don't have to go through this alone. We have worked with our Lifers community to put together this booklet of information, tips and questions, and we hope you will find it useful.

You can also find lots of information on our website. Please get in touch if you can't find what you're looking for. If we don't have the answer, we can signpost you to the people who do.

Shine Cancer Support

dealing with your diagnosis

Whether you have just received your diagnosis or you have been living with cancer for a long time, there is no right or wrong way to feel, act or be. Equally, there is no one-size-fits-all approach, with different diagnoses, prognoses and treatments.

Knowing that you have an incurable cancer can leave you feeling uncertain and you may want to know:

- How and when you will change physically, mentally and/or emotionally
- How this will impact on your daily life including your job or relationships
- What the treatment options are to manage the cancer
- Exactly how much time you have left to live
- If you can carry on working or if there is financial support available

It is normal to have lots of questions and it's up to you whether you think knowing the answers will help you to manage your situation. Some people prefer to take life as it comes and work on a 'need to know' basis, whereas others feel more in control if they have clarity. You might find it helpful to speak with your doctor, a friend or people in a similar situation to get their opinions too.

Treatments

Although your cancer can't be cured, treatment can sometimes shrink the cancer, slow its growth, help to relieve symptoms, or help you to live longer. Treatments could include one or a combination of surgery, chemotherapy, radiotherapy, immunotherapy and hormonal therapy. Your medical team should explain the options available to you, including any side effects.

Often, certain treatments will only be successful at controlling the cancer for so long, so regular monitoring will help you to decide on your next steps and whether you need to change treatments. The side effects of treatment can range from appetite loss and nausea, to constipation and sleep problems. Knowing this from the start can help you to plan ahead and make sure that you are in the best position to manage side effects as soon as they start.

"I remember how floored I was for so long after my diagnosis. But you will have fun again and you will do great things that make you happy. My coping mechanism has been nature. I go on hikes, I'm learning to sail. It keeps me positive and grounded."

—Fiona, breast cancer



"I found the Shine stories online and it made me feel so positive. Just hearing from someone else can really help. It made me feel that everything is going to be ok and not to give up."

-Hollie, sarcoma

"Do not Google! The information you find might not be relevant to your diagnosis, and could be out of date. Stick to the main cancer websites for your information."

-Heather, breast cancer

dealing with your diagnosis

Some things that may help:

- Find people to talk to. This may be a friend, family member, community group, or you may want to join the [Shine Lifers Facebook](#) group. Talking through your concerns can help to ease the emotional burden.
- Get as much information as you need from your consultant, clinical nurse specialist or charities. Think about what information will help you and don't be afraid to ask questions.
- Be kind to yourself. There will be up and down days so don't be hard on yourself when you're not feeling positive. Don't put pressure on yourself to be a certain way but know there will be better days.
- Accept offers of help. Depending on your symptoms or side effects of treatment, doing daily tasks may become difficult or exhausting. People often want to help and getting support can make you feel more in control of your life.
- Distract yourself. While it's not helpful to bury your head in the sand long-term, a little distraction can be useful as you come to terms with your diagnosis. Lose yourself in a podcast, box set or something else that you enjoy like art, exercise or going out with friends.

Caring for your emotional health

Living with an incurable cancer is tough and it's normal for your mood to fluctuate as you navigate treatments, scans and consultations. You'll also have to balance the regular things in your life with living with cancer, and this can be unsettling. You might feel a mix of grief, anger, sadness, shock, and denial, all the way through to acceptance and positivity.

An incurable diagnosis also means that you may be facing multiple lines of treatment. You may find that one treatment keeps you stable, or even shrinks your disease, for an amount of time, but that it later stops working. This may mean you have to try something else, leading to feelings of intense disappointment as well as anxiety and nervousness. You may also feel angry at the constant ups and downs, and all of the tough things that cancer has brought into your life.

None of this is easy. Below are some of the tactics the Shine team and our community use to help support our mental wellbeing through the tough times, but we also recognise that everyone will have their own way of coping.

"It's ok to be fatigued and scared and angry. Don't feel pressure to be positive all the time. Feel all those feelings. What you feel is what you feel – sit with it. Then when you feel ready, pick yourself up and look for the good things again."

-Michelle, breast cancer



dealing with your diagnosis

Recognise your feelings

Don't try to push your feelings down to just 'get on with it'. Allow yourself space to experience the emotions of living with advanced cancer. You might find it helpful to write down your feelings, talk to someone, read our blogs from people in the same position, or simply to sit with it.

Keep an eye on your mood

We know how frustrating it can be to have people telling you to 'be positive' - and you definitely don't need to be. However, it can be helpful to think about how you might be able to shift your mood or lift your spirits given how difficult a time this is. Whether it's practicing mindfulness or keeping a gratitude diary, finding things that allow you to focus on things other than your diagnosis can be really helpful. But more than anything, don't put pressure on yourself to feel one way or another.



Talk about it

Talking to someone you trust could be the key to releasing some of the mental weight that has built up in your head. Talk to other people who have incurable cancer, a close friend or family member, therapist, or a member of your spiritual community – do what feels right for you.

Stay informed

People are living longer lives with advanced cancer and there are different treatments, support and advice to help with that. Learning the facts and being an active partner in your own care can make you feel more in control.

Be realistic

Keeping up with responsibilities can be hard, so be realistic about what you can manage and draw on those around you for support. What is essential and what can wait or be cancelled? We can be guilty of wanting to achieve all the time, but you can't do everything. Remember that many people may offer help but be unsure of what they can do. If you can provide them with specific actions (such as doing your grocery shop or helping to clean your house), you may feel relieved while they will feel useful.

Control the things you can

It's easy to feel like everything is happening to you and that you have no choices. However, asking your consultant questions that are important to you, looking after yourself, or keeping a calendar to be organised are small things that can provide structure and help you to feel empowered.

Get professional help

Our range of activities, including peer support groups and workshops, can be helpful. Other charities such as [Mental Health Foundation](#), [Mind](#) and [Maggie's](#) offer one-to-one therapy or group activities, all of which can be really helpful as you cope with cancer. If you have consistently low feelings or you feel like you're losing hope, these could be symptoms of depression and you should speak to your consultant or GP. Remember that there is no shame in struggling mentally with an advanced diagnosis; you wouldn't be human if you didn't find it difficult.

Get support for your loved ones

Having cancer is tough, but so is supporting someone with cancer. Looking out for a friend, partner or family member, while trying to manage your own worries, energy and work can be hard. Your supporters might feel guilty about asking for help so you might want to let them know about our [Plus Ones Facebook group](#) or you could speak with your consultant, clinical nurse specialist or counsellor about help available.

“Accept that you will have times when you feel down –it’s ok to ask for help if you need it.”

–Meera, multiple myeloma

All the things we know are good for us can be really hard to do, even at the best of times! But taking small steps to look after your health beyond your cancer treatments can help you to feel mentally and physically better.

Moving your body

Exercising when you have cancer, and particularly through treatment, can help you to feel better, although we know getting the motivation to exercise isn't easy. Some of the documented benefits include reduced depression and anxiety, increased energy, muscle loss prevention, reduced pain, and improved sleep.

Physical activity is any movement that uses your muscles and more energy than when you're resting. This doesn't have to be a spin class or training for a 5k run. It can be a short walk to the shops, swimming, gardening, or dancing around your living room. Even low intensity exercise, such as yoga or pilates, can work wonders for fatigue and energy levels.

Speak to your doctor or nurse about the types of exercise that are suitable for you. If you've had a long period of rest or recuperation, you may want to see if you can be referred to a physiotherapist or an exercise specialist with special training in supporting cancer patients.

"Having cancer is like being on a rollercoaster blindfolded. You don't know how you will feel from one day to the next and nothing prepares you for the ups and downs."

-Ewan, sarcoma

"Before I joined Shine, I had feelings of loneliness, isolation and uncertainty. However, now I feel I am not alone with these feelings and it's OK to feel down, it's OK to cry, and it's normal to feel guilt around cancer."

-Naveed, Erdheim-Chester disease

"Then he said the words 'it's a rare type and there is no cure' and time stopped. That was not meant to happen. I was meant to have a fighting chance, but that had been taken away from me. I was totally devastated and numb."

-Louise, kidney cancer



Nourishing foods

Sticking to lean proteins, fruits, vegetables, whole grains, and limiting sugar, caffeine, salt, and alcohol are generally good ways to live your life, whether you have cancer or not. This might not sound very fun but it doesn't have to mean steamed veg all the way! [BBC Good Food](#), [Jamie Oliver](#), [Meera Sodha](#), [Rikmuni Iyer](#) and [Pinch of Nom](#) do some really simple, tasty recipes. You could also check out Ryan Riley, a food writer and founder of [Life Kitchen](#), as well as [Cooking for Chemo](#) where Chef Ryan Callaghan has worked on recipes that work well even if your sense of taste is playing up.

Constipation and dehydration are common difficulties when you're in treatment, so adding fibre to your diet and drinking plenty of fluids can help. There may also be times, particularly during treatment, where you lose your appetite. Don't put too much pressure on yourself to eat 'like normal'. Eat outside of the standard routine, choose high-fat foods or protein shakes to give you energy, try to liven up your tastebuds with a variety of foods, and eat little and often.

You have probably read about alkaline, ketogenic, dairy-free, raw or fasting diets, and while some of these may make you feel good, there is no scientific evidence that they can treat or cure cancer. You should speak with your doctor before making any major changes to your diet as they could lead you to lack certain vitamins that are important to keep you well.

Complementary therapies

Complementary therapies are generally therapies that are used alongside conventional cancer treatment to help manage side effects and support you to cope better with treatment. These therapies include things like massage, reflexology, reiki and aromatherapy, and many people find that they can help with relaxation, nausea and pain management. Many cancer centres offer complementary therapies and it can be worth finding out what is available as they can be a real boost when you're feeling physically or mentally low.



Alternative therapies

Alternative therapies are generally used instead of conventional treatment. While some people might tell you that an alternative therapy has cured their cancer or helped them to live longer, most alternative therapies are not backed up by scientific evidence. Many may not be completely safe, and some can cause actual harm. You should always speak to your doctor or clinical nurse specialist before undertaking any new therapies (complementary, alternative, or otherwise!) and look at reputable sources of information for details.

Memorial Sloan Kettering in the US has a useful website which looks at various treatments and supplements and whether they are likely to be safe or harmful.

Managing pain

When you're in pain, it can affect everything from your sleep and appetite to the simplest tasks in your daily routine. Pain can be a sign that you have an infection, your cancer is more active, a symptom of your cancer, or it could be a side-effect of a treatment you are having.

Keep a pain diary to track and understand your pain. It could help your clinical team to plan your treatment. This could include surgical or medical treatments such as nerve blocks, radiotherapy, or simply over-the-counter drugs. If you have religious or cultural reasons to be concerned about taking medicines, share that with them.

Lots of people can help you to manage your pain such as your GP, district nurses, palliative care specialists or anaesthetists. While palliative care can sound really scary, palliative teams are often experts in pain management, and tend to focus on improving your quality of life, so if pain is an issue, you should consider asking for a referral.

While everyone has different levels of physical pain (including none at all), one thing our community consistently experiences is fatigue and brain fog. While there is no magic bullet to managing these, keeping active, eating well, trying not to multitask, aiming for good quality sleep at night, and getting support with mental health issues such as anxiety can help.



Clinical trials

Through clinical trials, doctors can find new ways to improve treatments and the quality of life for people with disease. There are two main types of trial: interventional studies which aim to find out about a particular treatment, and observational studies that aim to find out what happens to people in different situations.

The benefit of joining a clinical trial is that you may get access to a new treatment that may be better than your current treatment, and you will be observed closely by the research team. However, there may also be treatment side effects, it may not offer any benefit, and it may require extra time and energy to attend appointments, as well as requiring more scans and blood tests.

According to [ClinicalTrials.gov](https://clinicaltrials.gov), almost 1000 cancer studies are currently recruiting research participants in the UK. If you're interested in learning more about clinical trials, you should start by speaking to your consultant or clinical nurse specialist. It's important to know that trials are not just for people who have run out of treatment options; in fact, it can be more difficult to get on a trial if you are very unwell, so if trials are of interest to you, there is no harm in starting your research early. You can find out more about clinical trials on the [NHS website](https://www.nhs.uk). You can also search for trials through organisations such as [Cancer Research UK](https://www.cancerresearchuk.org), [Institute of Cancer Research](https://www.institutecancerresearch.org) and [National Institute for Health Research](https://www.healthresearch.org.uk). [My Tomorrows](https://mytomorrows.com), which is based in the Netherlands, is also a useful site which will search for clinical trials around the world which may be of use to you.

relationships

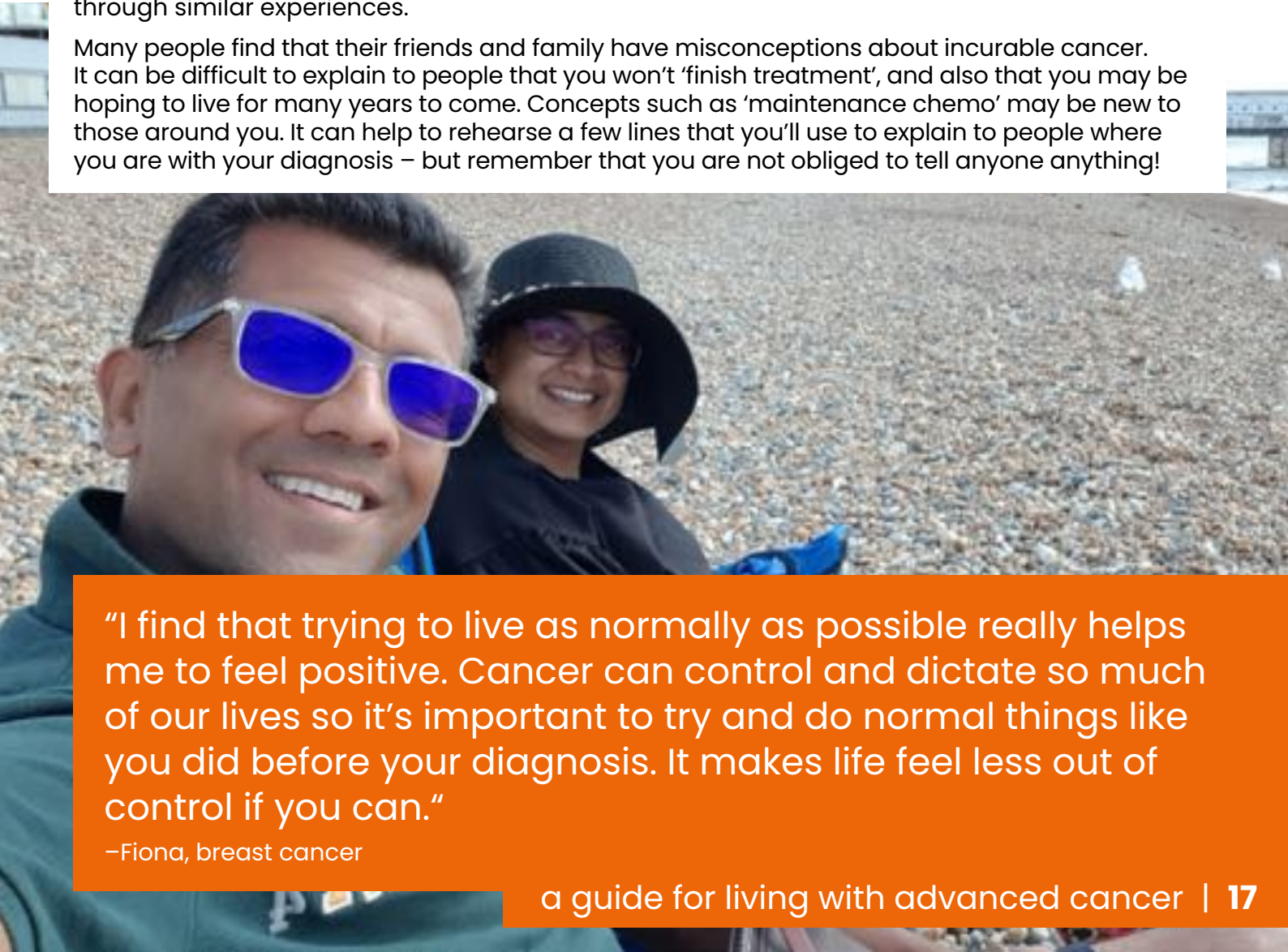
Having advanced cancer doesn't just affect us, but everyone in our circles. Our parents, children, siblings, friends, neighbours or colleagues will all be impacted in different ways and some relationships will become strengthened, while others may become strained or disappear completely.

How your relationships might be affected

It can be difficult to predict which relationships will be affected by your diagnosis – your best friend may not feel able to cope with what you tell them, whereas a work colleague may really come through for you. This can feel awful and may not be what you expected but it's important to understand that this is not about you; everyone manages things in different ways (it just may not be the way we'd like!).

As with anything in life, you may lose some friends along the way, but you could also gain new ones. Our Shine community – especially our Lifers Facebook group – is full of people going through similar experiences.

Many people find that their friends and family have misconceptions about incurable cancer. It can be difficult to explain to people that you won't 'finish treatment', and also that you may be hoping to live for many years to come. Concepts such as 'maintenance chemo' may be new to those around you. It can help to rehearse a few lines that you'll use to explain to people where you are with your diagnosis – but remember that you are not obliged to tell anyone anything!

A photograph of a man and a woman smiling outdoors. The man is in the foreground, wearing blue sunglasses and a green jacket. The woman is behind him, wearing a black hat and sunglasses. They are standing on a gravelly surface.

"I find that trying to live as normally as possible really helps me to feel positive. Cancer can control and dictate so much of our lives so it's important to try and do normal things like you did before your diagnosis. It makes life feel less out of control if you can."

–Fiona, breast cancer

getting support

You could be someone who retreats into themselves, particularly when you are feeling low, whereas others might look for support from lots of people to keep them boosted. There is no right way to be. Talk to your friends, family and colleagues about when and how you want to be supported. People often want to help, but may not know how.



"I have a bad habit of alienating myself when I have an acute period of feeling low. Having visitors can be exhausting and awkward. I always regret it after though. I wish I hadn't set it up that way as now people think I don't want them there. I do but I just need to set boundaries."

-Emma, myelodysplasia

"Don't expect people to know how to help you – you should be honest with them and ask them for help."

-Hollie, sarcoma

Having cancer doesn't mean you don't want to have sex anymore (although it's ok if you don't!). However, treatments can throw in obstacles such as erectile dysfunction, sexual pain, dryness, or simply not having the energy to have sex. You may experience physical or emotional changes that can make you feel low or 'unsexy', and your partner may also worry about touching you if you're unwell or in pain.

Whatever you are feeling, you're not alone. Many doctors and nurses are not well versed in talking about sex, though your clinical nurse specialist may be a useful first point of contact for any questions or worries. They should be able to provide support, advice, or in some cases medication, to help you – or at least let you know where you can go for help. Find out more about sex after cancer on our [website here](#). You may want to speak to a psycho-sexual therapist about your experiences or feelings; you may also be able to be referred to one via your consultant or clinical nurse specialist though many also do private work (if you can afford to pay).



dating

Dating can be tricky at the best of times. Throw cancer into the mix and you'd be understood for not wanting to put yourself out there. But if you are looking for romance, closeness, or simply companionship, there is no reason why you shouldn't dive into the world of dating, regardless of your diagnosis.

Sure, you may feel your future is uncertain, but in reality, so is everyone else's. It may even make you change your outlook on dating and can add a new dimension to what you are looking for.

Our body image and self-esteem can be affected when we have cancer, which can be particularly hard in this modern world of online dating. It can also be overwhelming thinking about when or how to mention your health status, reveal your scars, or let them into your treatment schedule. Take it at your own pace and prioritise making connections with others, whether romantic or not. Building your social connections and support system can also help you to feel content and loved in other ways. You may also want to join [Shine's Dating after Cancer Facebook group](#) to talk to others navigating the dating world.



supporting children

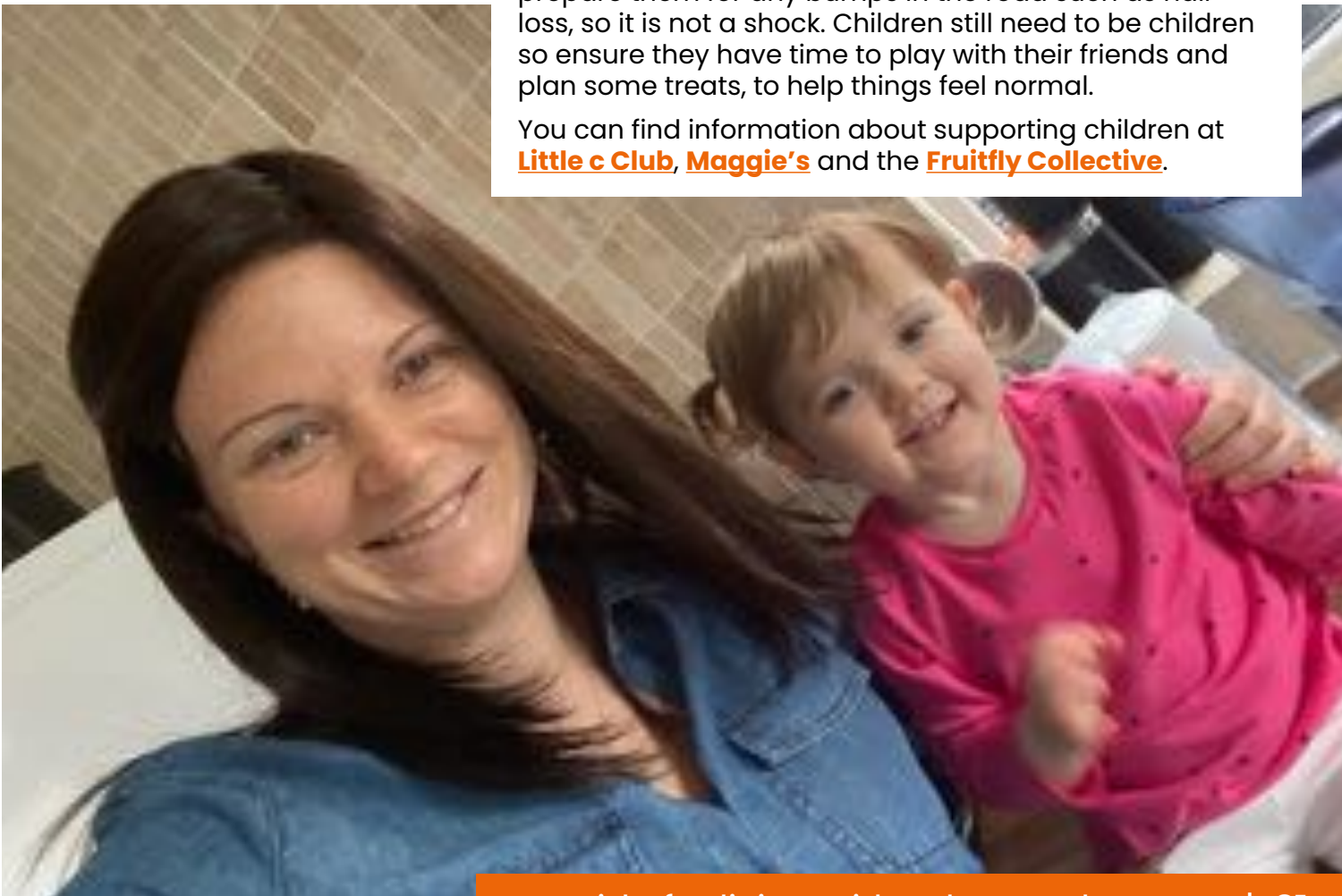
All we ever want is to protect our children and make them happy. Becoming ill can be particularly hard if you're worried about the impact it will have on your little ones. Our community tells us that honesty is always the best approach.

Some people do choose not to tell their children about their diagnosis. While this approach is definitely valid, children can often sense that something is wrong and will often fill in the gaps if they don't have accurate information. Children don't need to know every detail, but it's helpful to give them enough that they understand the situation and how it might affect them. It can be helpful to ensure that people such as wider family members, their teachers, or their child minders know what's going on so that they are prepared to answer any questions or can offer support. Many schools also have a pastoral support team who can keep an eye on your child or offer support to them within the school environment.

Children of different ages will cope with a parent having cancer in different ways. They may be completely open with you and express their feelings or they might become distant or bury their emotions and continue as normal. Encourage them to speak with someone. They may benefit from talking to a counsellor or therapist to make sense of the diagnosis.

Try to keep to familiar routines so there is not too much upheaval, assure them that they are safe and loved, and prepare them for any bumps in the road such as hair loss, so it is not a shock. Children still need to be children so ensure they have time to play with their friends and plan some treats, to help things feel normal.

You can find information about supporting children at [Little c Club](#), [Maggie's](#) and the [Fruitfly Collective](#).



menopause

Menopause typically occurs in women between 45 and 55 years of age and is part of a natural ageing process. However, if you have cancer as a younger adult, there is a possibility that your treatment may bring about an early menopause and lead to a lot of symptoms you weren't necessarily in the market for. Treatments that may bring about an early menopause include chemotherapy, hormone therapy, surgery to remove both ovaries, or radiotherapy to the pelvis.



In some cases, menopause will only be temporary and once a particular treatment finishes, your periods will return and your hormones will rebalance. In other cases, it will be permanent, or you'll take drugs which put you into menopause for a longer period of time. Your doctor and specialist nurse can explain if the treatment you are having is likely to cause an early menopause, and whether this may be permanent or not.

If you are receiving a treatment that could bring on the menopause, the change in hormone levels can lead to symptoms including hot flushes, loss of libido, difficulty sleeping, vaginal dryness, aches and pains, and weight gain. While the severity of symptoms can vary, menopause brought on by cancer treatment can also feel quite dramatic as it occurs suddenly, rather than as the result of a natural decline in hormones.

Depending on the type of cancer you have, you may be able to take hormone replacement therapy (HRT) which can reduce the symptoms and help protect your bones and heart. For some cancers, such as a hormone-sensitive breast cancer, it is not recommended that you take HRT; however, there may be other medications that you can take to help cope with the symptoms of menopause. Living with incurable cancer and being on treatment can bring a lot of pain and side effects but menopause can (and should) be managed if it causes you distress or disturbances. You may need to push your medical team to help you – or find someone who can – but doing so can be very important for your quality of life.

There are a lot of practical ways to reduce menopausal symptoms and your doctor can also prescribe drugs or treatments that can help. Some tools and techniques to try include:

- For hot flushes, wearing natural fabrics, keeping the room temperature cool, reducing spicy foods, and using cooling pillows. Where hot flushes (or night sweats) become problematic, there is evidence to suggest that some anti-depressants in low doses can reduce their frequency and severity.
- Using creams or lubricants for vaginal dryness – just make sure they don't damage condoms if you're sexually active. Many women, regardless of cancer type, can also take local oestrogen via pessaries or gels to help improve vaginal dryness or pain during sex.
- Practising relaxation techniques and holistic therapies, such as massage and acupuncture, to help to boost your mood and prevent feelings of irritability.
- Many people experience disturbed sleep, so try mental and/or physical exercise in the day, reducing caffeine intake, and keeping your bedroom cool for sleeping. If your sleep is being disturbed by night sweats or hot flushes, look at ways to manage these.
- Cognitive behavioural therapy can also help to manage some symptoms of menopause. While it does not change the underlying symptoms, it can help you to develop techniques and strategies to cope with them.

An early menopause can seem like another loss in a life already significantly impacted by cancer. The emotional impact of going through this change can be very difficult – and it is understandable that you may need extra support. Speak with your doctor first but you can also join Shine's [**Menopause after Cancer Facebook group**](#) for people going through similar experiences. [**Shine's website**](#) also contains videos about menopause which may be of interest.

Cancer and cancer treatment can both impact on your fertility. If having a child is something that you want, it's important that you discuss this with your medical team and find out how your diagnosis may impact on your fertility and ability to carry a child.

You should speak to your consultant about fertility preservation before your treatment starts; you can ask to be referred to a fertility clinic or an onco-fertility specialist who will understand more about your situation and will be able to talk to you about your options for fertility preservation, the long-term effects of treatment, and the next steps you may wish to take.

You may want to talk to a counsellor, your partner or a trusted friend about what having a child could mean if your diagnosis also means that you are facing a shortened life expectancy. There will not be a 'right answer', but it's important to think through the implications for you, your child and your partner and family.

If you're unable to have children, this can be devastating and can feel like another blow on top of your diagnosis. Many members of the Shine community have found it useful to speak to someone such as a counsellor about these feelings, if only to gain peace of mind about the decisions made and to acknowledge feelings of loss.

work – what to do now?

If or when you choose to stop working is a personal decision. Some people want to continue working to maintain normality or may have to for financial reasons. You may want to stop or reduce your hours so you can spend more time with your family, travel, or to focus on your treatment. You may also find that working while you have cancer or are in treatment is very tiring and decide to cut back on hours so that you can manage your energy.

Depending on your job, your ability to work may be affected, particularly if you have fatigue, drowsiness, memory problems or energy loss. If work has been the major focus of your life, it can be difficult to adjust to not working. As with many other things, a change in your work can feel like another loss you have to bear. It may help to talk to someone about what to do, such as a close family member or friend, or an HR advisor at work.

Your rights in work

As someone living with cancer you are covered by either the Equality Act 2010 if you live in England, Scotland or Wales, or the Disability Discrimination Act if you live in Northern Ireland. It is unlawful for your employer to treat you less favourably because of your cancer diagnosis. Employers have a duty to make reasonable adjustments to support you including lighter duties, flexible hours, and time off to attend appointments. You are also covered in terms of recruitment, terms and conditions of employment, benefits, opportunities for promotion and training, and ending your employment.

Depending on your employer, you may have access to disability leave, statutory sick pay, occupational sick pay, pension rights and work-related private medical insurance. If you give up work, you give up the rights associated with your employment. Check your employer's policies or speak to HR about your rights. You may also find it useful to speak with [Citizens Advice](#) or the [Equality Advisory Support Service](#) for free, confidential advice.

"I probably would have got a new job by now but my employer has been really supportive. I have had chemotherapy every two years for a recurring cancer and they are understanding about any time off I need. It's important to know your rights."

–Emma, myelodysplasia

work – what to do now?

Critical and terminal illness cover

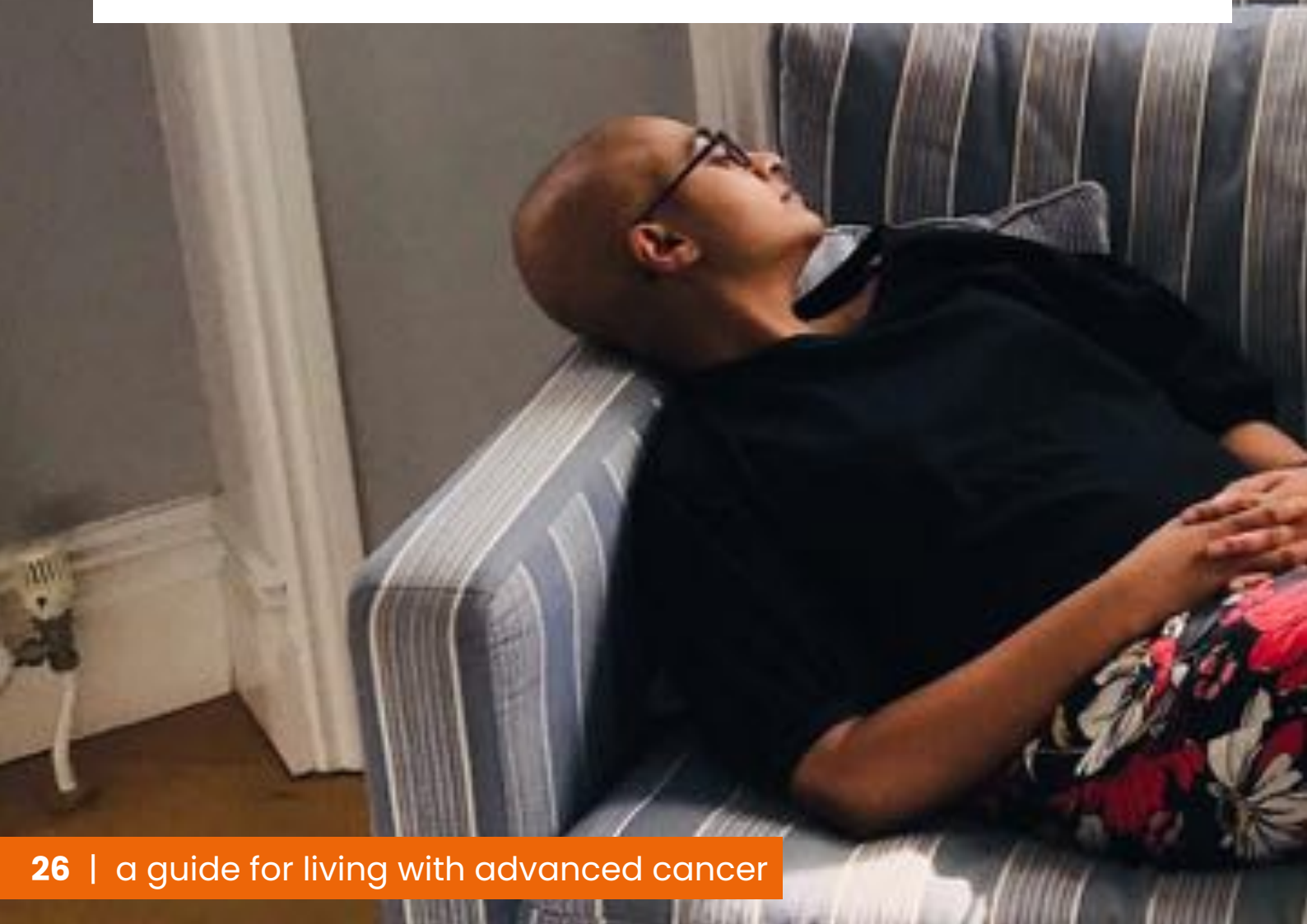
If you've taken out critical illness cover, now is probably the time to claim it as it should pay out as long as you've kept up with your payments. It usually results in a lump-sum, tax-free amount being given to you. You may also have terminal illness cover as part of your employment benefits. Speak with your HR team to see what they offer. If you leave or change your job, you might want to consider making alternative insurance arrangements.

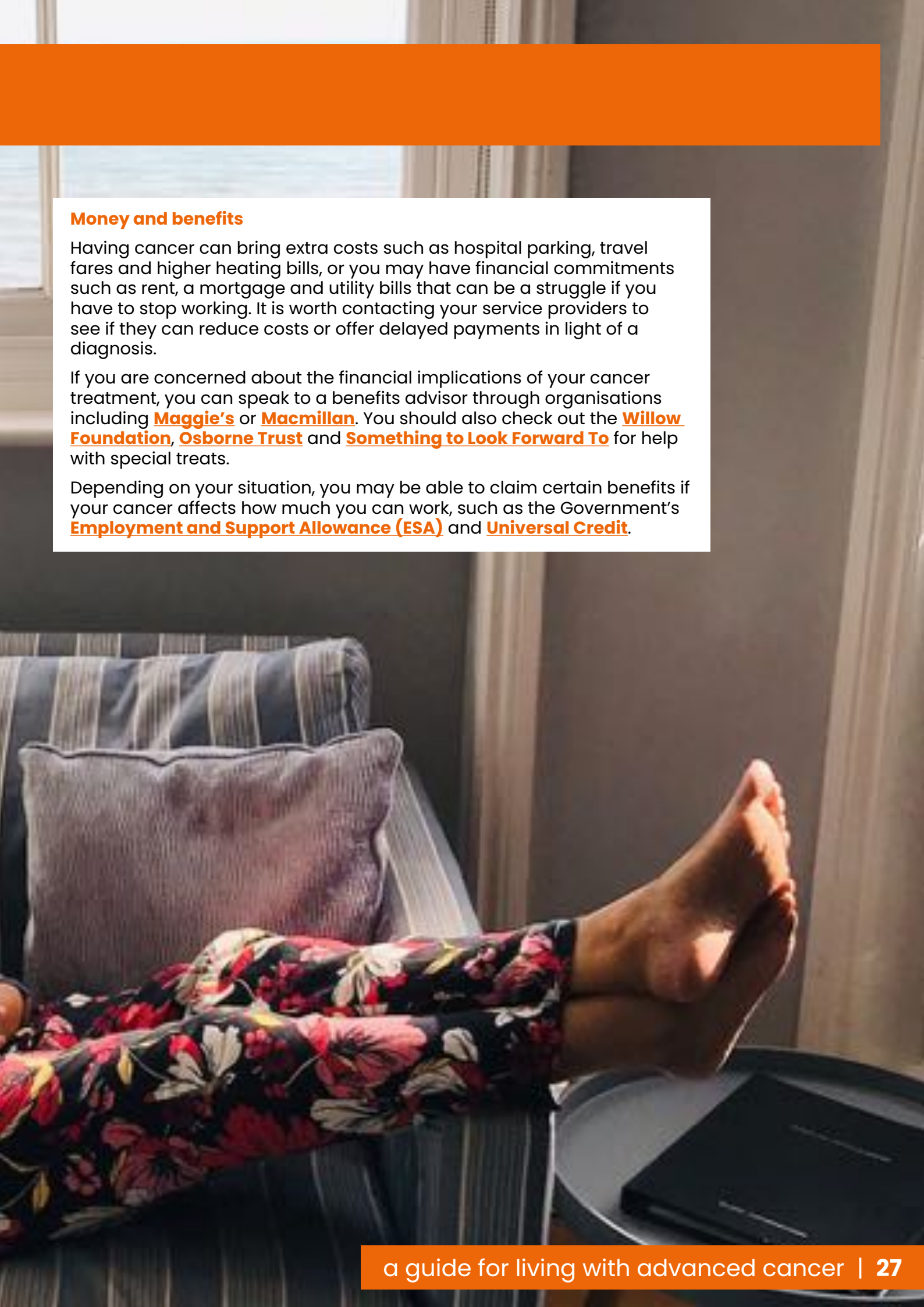
Terminal illness is included as standard with most life insurance policies. Generally, you can make a claim when you have a prognosis of 12 months left to live, or you can allow your policy to continue, after which it would pay out to your family after death. Check your policy details and consider what works best for you.

Early retirement and accessing your pension

If you want to take early retirement on health grounds or for personal reasons, it is essential to take advice from your pension administrator. You may be able to take early payment of your pension on the grounds of ill health, but this will depend on the rules of your own particular pension scheme.

Getting advice from an independent financial adviser about the various options open to you may help you get a higher income from your pension. Early retirement is always a big decision, particularly if you're making this choice because of your health. There are places to get help such as [**Macmillan**](#).





Money and benefits

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills, or you may have financial commitments such as rent, a mortgage and utility bills that can be a struggle if you have to stop working. It is worth contacting your service providers to see if they can reduce costs or offer delayed payments in light of a diagnosis.

If you are concerned about the financial implications of your cancer treatment, you can speak to a benefits advisor through organisations including [**Maggie's**](#) or [**Macmillan**](#). You should also check out the [**Willow Foundation**](#), [**Osborne Trust**](#) and [**Something to Look Forward To**](#) for help with special treats.

Depending on your situation, you may be able to claim certain benefits if your cancer affects how much you can work, such as the Government's [**Employment and Support Allowance \(ESA\)**](#) and [**Universal Credit**](#).

accessing palliative care

Palliative care is treatment, care and support for anyone with a life-limiting illness, and their family and friends. There are often misconceptions that you only access palliative services as you near the end of your life, but it can be used at any stage of an illness. The aim of palliative care is to help you have a good quality of life. This includes being as active and as comfortable as possible by relieving symptoms and side effects of treatment. It may also include support for psychological, social or spiritual issues that you face.



You may need to do a bit of research to be referred to palliative care – even some doctors aren't aware of all that palliative care teams can offer. In some cases, your GP can refer you while in others you may be able to self-refer. Many oncology and haematology centres also have links with hospital palliative care teams or local hospices.

Palliative care can address a broad range of issues, integrating an individual's specific needs into care, including:

Physical needs: If you are experiencing physical symptoms from either your cancer or your treatment such as pain, nausea, vomiting or insomnia, palliative care specialists can provide you with medicines or help with things like nutrition and sleep therapy.

Emotional needs: Palliative care specialists can provide resources to help you and your family to deal with the emotions that come with an advanced cancer diagnosis and cancer treatment. Depression, anxiety, and fear are just some of the concerns that can be addressed through palliative care.

Spiritual support: Some people find having cancer brings them closer to their spiritual beliefs. An expert in palliative care can help you to explore your beliefs and find a sense of peace. They may also have links to relevant chaplaincy services.

Social needs: Palliative care teams, particularly where they are linked to hospices, can often organise help for things like washing, dressing, eating, or accessing equipment to help with your mobility, if required. They can also help to arrange transport to and from your appointments or plan a family meeting to help you explain what you need.

Family and friends: It's common for your networks to feel overwhelmed by the uncertainty of your situation. They may also have extra responsibilities placed upon them or feel stressed or anxious about the future. All of this can also add to stress and can also sometimes lead to depression or anxiety. Palliative care specialists can help families and friends cope and give them the support they need – or make referrals to others who can help.

Practical help: Palliative care specialists can also assist with financial and legal worries, insurance questions, and employment concerns. You may also want to talk to them about advance statements (see next page) and facilitating communication among family members, caregivers, and members of your oncology care team.

“When I couldn't walk they helped me to get a wheelchair, a new bed, a Blue Badge and counselling. They made my life a lot easier, financially and physically.”

– Hollie, sarcoma

planning ahead

Talking about and planning for death can make us feel frightened or uncomfortable. Yet it happens to all of us and being more open about it can make it feel less of a taboo subject. It's okay if you don't want to think about it right now and would rather wait until you feel you're in the right headspace. When you are ready, it can help to make a list of things you want to consider and take it in small stages.

There are a number of available tools to ensure that wishes related to your care and end of life are documented. These include:

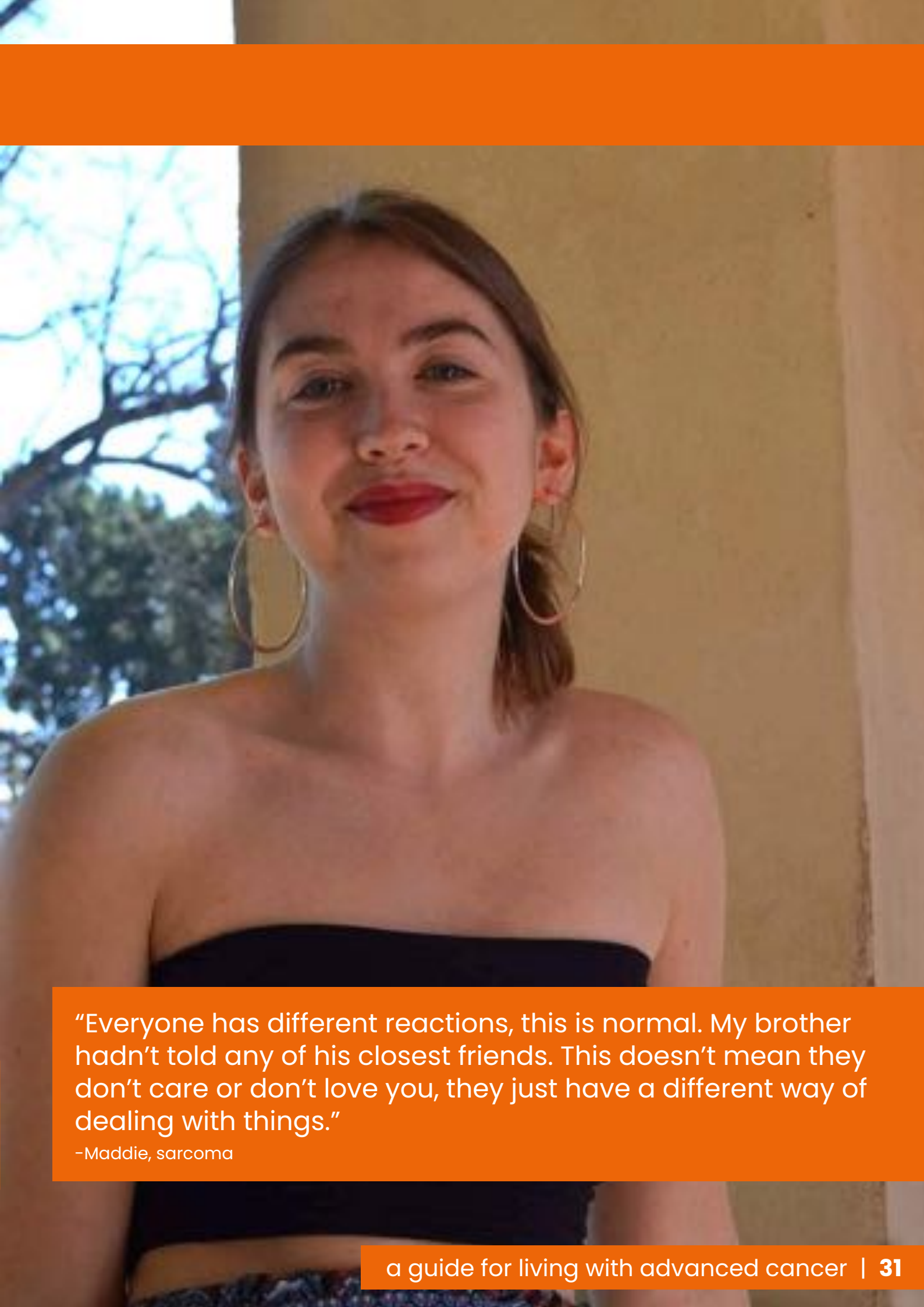
- **Lasting power of attorney for health and welfare**, through which you appoint one or more people to make decisions on your behalf. This has a cost associated with it (£82 at time of writing in 2022) and may take some time to process.
- **Advance decision form (also known as a living will)**. This allows you to document the treatments that you do and do not want. These are legally binding and free to complete.
- **Advance statement**. This is not a legally binding document but does have legal weight and can allow you to outline priorities related to your care, the location of that care, and the nature of your care (e.g. if a certain religion or type of care is important).

You could also consider the following:

- Writing a will and deciding how you will want your possessions distributed. Everyone should write a will anyway and it means you won't have any songs you'd hate at your funeral.
- Making your funeral arrangements to take the pressure off your loved ones. You can make decisions that will make the event meaningful. It can also save money as the costs will be at today's prices.
- Writing letters to your closest friends or family, such as a letter for when your child turns 18 or a note of special memories for an old friend.

"Once you do the organisation of the dying bit, you can get on with the living bit."

- Michelle, breast cancer



“Everyone has different reactions, this is normal. My brother hadn’t told any of his closest friends. This doesn’t mean they don’t care or don’t love you, they just have a different way of dealing with things.”

–Maddie, sarcoma

planning ahead



Talking about death

Talking about death to people you care about is not easy. But when we don't have honest conversations about this it can increase feelings of distress, loneliness and grief. Decide who needs to know, how much information they need, and how you're going to tell them. For some people, having a frank conversation feels right, whereas for others an email would suffice. Remember that those who love you may find it difficult to talk about your death and you may need to spend a bit of time preparing them for the conversation first. Compassion in Dying has a [useful booklet](#) on how to start this conversation with friends and family.

Take joy in the small things

You may have always wanted to skydive, go on an African safari, or visit the Taj Mahal and, given your diagnosis, you might now feel the pressure to fill your life with magical experiences. Just be realistic about what you can do and what really brings you joy. Often the most joy can be taken from the little things in life. Being with family and friends at home, reading a book by the fire, getting out into nature with your dog. Don't feel pressure to tick everything off a 'bucket list'. If you have children, remember that the thing they value most is time with you. While a trip to Disneyland may be on your wish list, your children may benefit just as much from spending time with you doing things they love such as swimming or camping.

Useful support and apps

- **Bereavement counsellors.** You might find talking to a bereavement counsellor or therapist beneficial. You can access bereavement counselling via your GP, a local counselling service, a registered psychotherapist, or charities including [Marie Curie](#) or [Cruse](#).
- **Spiritual care.** Hospice chaplains can help you to talk about things that are distressing you. Chaplains provide spiritual care regardless of your religion or beliefs.
- **Funeral help.** You can find information about how to organise your funeral and who to do it with on the [Funeral Services Guide](#).
- **Support for your family.** You could direct your family and friends to charities and organisations to help them deal with grief, such as [Cruse](#), [The Loss Foundation](#) or [Grief Encounter](#) that is specifically for children.
- **Legacy sites.** There are lots of websites and apps for you to record messages, share memories, safeguard your digital legacy and document your funeral wishes. One site, called [Keylu](#), also offers the ability to store – in a safe way – details of your financial accounts, social media and your wishes, so that your family can access them. If you're living with an incurable diagnosis, Shine may be able to offer you a free subscription. Just drop us a line at hi@shinecancersupport.org with Keylu in the subject line. Alternatively, you can get a discount on this service via Shine's link [here](#).
- **Getting to grips with end-of-life.** [Compassion in Dying](#) can help you with how to talk about death, how to plan for it, and how to record your wishes. Hospice UK's [Dying Matters](#) campaign has resources to help you, your family and friends to have the conversation around death and dying.

tips from the community

We asked our Shine Lifers community for some of the things they want to pass on to others with advanced cancer.

- Don't be afraid to ask your consultant what something means, to repeat something or to ask any questions. **Paul, brain tumour**
- Have a glass of wine, eat the cake, enjoy a long soak in the bath. Life's too short not to. **Michelle, breast cancer**
- Having a sofa day is a valid choice! I thought getting my diagnosis would change me and I would stop 'sweating the small stuff', but I'm still me so I do still get wound up about stupid things! However, taking time to pet the cat or have a short walk helps me reset and try and not let these things get to me – life is too short! **Morag, multiple myeloma**
- Follow your own judgement and make your own decisions. I'm neutropenic which means I have a higher risk of getting serious infections. I could choose not to do anything but I want to live my life to the fullest. Take the trip, live your life. **Emma, myelodysplasia**
- Keep active, especially getting outdoors, even if you don't want to. You will feel better afterwards. **Heather, breast cancer**
- Don't feel guilty about playing the cancer card once in a while – life is short, particularly for us Lifers, so if you don't want to do something or see somebody, then don't! Be selective in what you do and with whom; prioritise the people and plans which make you happiest. **Sarah, multiple myeloma**
- Don't be hard on yourself if you can't do as much with your kids – even just sitting with them on the sofa and giving them a hug is being together. **Laura, multiple myeloma**
- Having a positive mindset isn't about being happy all the time. It's knowing that when you're sad, you will be happy again. **Hollie, sarcoma**

useful questions

Questions that you may want to ask

- What does advanced cancer mean for me? What are my options?
- What are my treatment choices? Which do you recommend for me and why?
- Are there any clinical trials specifically for my cancer?
- How can I manage the symptoms of my advanced cancer or the side effects of its treatment?
- What complementary therapies could support me?
- Who is in my medical care team and how can I contact them?
- Who are my local palliative care specialists and what support can they offer me? How can I be referred to palliative care?
- How can I make sure I have the best quality of life possible – that I am comfortable and free of pain?
- How can I get help with financial and legal issues?
- Is my ability to work likely to be affected, and how? What do I do when I want to give up work?
- Will my family be ok when I'm no longer here? What steps can I put in place now?

notes

notes

keep in touch

Thank you for reading our booklet for young people living with advanced cancer. We hope it's offered some clarity and reassurance while navigating the emotional, physical and practical challenges.

We have covered the topics that get discussed the most by our community, and we are here when you feel ready. We recommend joining our **[Lifers Facebook group](#)** as a starting point. It's a chance to connect with people your age that are going through similar experiences, to ask questions without judgement, and give each other a boost if times get tough.

We are a small team here at Shine and we design all our services based on your needs. So, get in touch with us if you need specific support or services. If we don't have it, we can signpost you to someone who does.

We'd love to meet you!

To find out more information, check out our website, follow us on social media, or drop us an email.

hi@shinecancersupport.org
[shinecancersupport.org](https://www.shinecancersupport.org)

 [shinecancersupport](https://www.instagram.com/shinecancersupport)

 [shinecancersupport](https://www.facebook.com/shinecancersupport)

 [@ShineCancerSupp](https://twitter.com/ShineCancerSupp)

 [shine-cancer-support](https://www.linkedin.com/company/shine-cancer-support)

 [shine cancer support](https://www.youtube.com/shinecancersupport)