



shine
CANCER SUPPORT

**When your cancer is
treatable but not curable**

A Guide for Living with Chronic Cancer



shinecancersupport.org

Shine Cancer Support

This is a guide for those in their 20s, 30s, and 40s who are living with chronic cancer. These types of cancer can be managed for a long time, sometimes without treatment, but it doesn't go away.

Chronic cancer doesn't fit neatly in a box. Your doctors may want to 'watch and wait' before they give you treatment, or you may be given treatment but told your cancer will return. All of this can be difficult to understand and even harder to explain to others, especially if you don't 'look' like you have cancer. It might make you feel uncertain, frustrated or isolated, even within the cancer community.

Shine is here to provide you with support and guidance. We focus on the emotional, physical, and practical aspects of chronic cancer such as dealing with relationships, living with uncertainty, and work and money. We leave the medical information to the doctors and nurses.

We know a lot of cancer support caters to those much younger or much older than you. Shine exists because there are a lot of different issues specific to this time of your life. To help you navigate these

and meet with others who understand, we run workshops, programmes, meetups, and online support.

We have a chronic cancer community who meet regularly to support each other, so you don't have to go through this alone. They helped write this booklet of information, tips, and questions, which we hope you will find useful.

There's even more information on our website. Do get in touch if you can't find what you're looking for and if we don't have the answer, we can point you in the right direction.

There's never a good time to get cancer but we're here so you don't have to go through this alone.

Dealing with a diagnosis

You may feel many different emotions when you are diagnosed with chronic cancer, including feelings of disorientation, shock, sadness, and uncertainty about your future.

The life you had planned may look different and you might not know where to start or how to navigate the appointments, treatments, and difficult conversations ahead.

Embracing and sharing these feelings can help you to come to terms with what your diagnosis means for you and those around you.

Your treatment options might be different to others with different types of cancer which can be cured – or you may not need treatment right now. You might need regular blood tests and scans, and go through cycles of recurrence and remission. Every cancer diagnosis is different, depending on your cancer type, treatment plan, age, and overall health.

There are other questions you might have such as:

- How will I explain this to my family and friends?
- How is this going to affect my job or other responsibilities?
- What is my prognosis?
- How do I ensure I have a good quality of life?
- What counselling or support is available?

It is important that you feel comfortable with your medical team. Make sure to share with them anything that can make you feel more supported, including things like the name you like to be called or your pronouns.

Emma: “I wish I had been given practical advice to remove barriers like knowing that I didn’t have to pay for prescriptions, access to specialist counselling, and tips to streamline the process of navigating the NHS and appointments.”

Some things that may help

Be kind to yourself. We know this is easy to say and hard to do! 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.

Get as much information as you need or want from your consultant, nurse specialist, GP or charities. Ask questions and if you don’t understand the answer, ask them to explain in plain English or simple terms.

Think about what you need right now. Whether it is time away from people to process, talking with a friend, family, or cancer community, or to read

David: “When I first found out, I wanted a sense of hope. This came through reading other people’s stories of cancer. I wanted to know that people could still live well, go to work, have a social life, and that there is a future.”



clinical resources to help you understand your diagnosis. This is about what works best for you.

Make a note of things. It’s common to experience brain fog and for things to be harder to remember, so you may need more reminders than before. This could include when you need to attend appointments, screenings or tests, the treatment options available to you, and how to keep as active and well as possible. Put reminders in your phone so that you don’t miss anything important.

Accept offers of help. You may need some time to ground yourself in the reality of the diagnosis, as well as any symptoms or treatment side effects. Doing daily tasks such as cooking, cleaning, school runs, or life admin may feel difficult or exhausting. People often want to help but don’t know how, so accept their offers and reduce your responsibilities.

Living with uncertainty

The uncertainty of a future that has to fit in hospital visits, treatments and side effects can affect people in different ways. Some people want to focus on living in the present, others can feel sad or overwhelmed, or some may feel grateful for being able to live with cancer. While you can't get rid of uncertainty, there are some ways to deal with it.



Asking for what you need

Be an active participant in your care and focus on what you can control. Ask questions about your monitoring and treatment, your team, or the support available to you – anything that will give you some clarity and peace of mind.

Remember that you can disagree with your doctor's advice, ask for a second opinion, and request a copy of your medical records. Know when you need help managing your emotions and reach out to people for support. There is a wealth of information and

there are communities that can help or signpost you in the right direction.

Managing long-term treatment

The goal of chronic cancer treatment is to keep the cancer under control and you can often undergo multiple cycles of remission and recurrence. At different stages, you may find yourself wondering whether the treatment has worked, what side effects are on the horizon, when the next treatment will be, or how it is going to affect your job, relationships or social life. While doctors will have

some answers, they can't be sure how the treatment will work for you or the specific effect on you.

Your schedule might not feel like your own so taking small steps to have a sense of control can make things seem a bit more manageable. Some members of Shine have planned something nice to do after a big appointment while others have made arrangements with work and family in advance to help reduce responsibilities.

The contrast of moving from active treatment to remission or 'watch and wait' can also be quite jarring. Not only is the clinical team not around as much, but during this quieter time you may be emotionally absorbing what you are going through. Make sure to think about ways of supporting your mental health, whether that's

through counselling, taking part in a Shine activity, or building in some time to reflect.

Maintaining your quality of life

It's ok to tell your team what's important to you, because treatment isn't just about surviving, but ensuring you have a good quality of life. Take one step at a time and think about what you need to live a good life – this could include socialising, good energy levels, pain control, or mental wellbeing. Ask your healthcare team what your options are. For example, if you are having intolerable side effects to medication, there might be an alternative or things you can try to improve them.

Meera: "You might be going on holiday and you want to enjoy it without feeling tired or be sure that you can eat the food you want to eat. Ask if you can reduce your treatment dose for that period. It is always worth asking."

If you're feeling anxious, depressed or even a bit low, know that you are not alone. Living with a cancer diagnosis can be very stressful, so you might consider professional support such as counselling or attending a Shine event or programme. You may also want to build in some additional relaxation activities such as going for a walk, listening to music, or meditation. We are all unique so what works for one person may not work for another, but this is a useful time to explore what works for you.

While living with cancer is uncertain, making the most of the times when you feel good can also make you feel better about times when you need to go into hibernation mode.

Many oncology and haematology services have specific psychological support available, so ask your clinical nurse specialist if you'd like to find out more.



Emma: "Your survivorship will be longer than older people - it gets to the point where, if you are going to have this for 70 years, then you need to be happy with the drugs that you are on."





Dealing with 'watch and wait'

'Watch and wait' or 'active monitoring' means that your clinical team will closely monitor your condition, without providing any treatment, until symptoms appear or change. This can be unsettling, but this is a standard approach for those with certain types of cancer.

To bring you some reassurance, ask your healthcare team for the signs and symptoms to look out for and make sure you're clear about what monitoring you need to stay on top of, like blood tests or scans. In the meantime, try to look after your health by eating well, doing some exercise, not smoking, and cutting back on alcohol. When the time comes, you will be in the best position to start treatment and at a lower risk of complications.

If you're unhappy with any aspect of your care or you need further information on your active monitoring and what symptoms to look out for, speak to someone in your healthcare team.



Caring for your physical and mental health

Moving your body

Doing activities which move your body can be beneficial for increasing energy, preventing muscle loss, reducing pain and anxiety, and improving sleep. This doesn't have to be a high intensity workout or marathon training. A short walk to the shops, swimming, shopping, or a dance class can work wonders for fatigue and energy levels.

There may be times when exercise isn't advised, such as after certain types of surgery, but there is increasing recognition about the benefits of exercise, even throughout treatment. Speak to your doctor or nurse about the types of exercise that are suitable for you, or seek expert advice from someone qualified to work with cancer patients. [Move Against Cancer](#) is a useful charity that specialises in supporting people to get active after a diagnosis.



Getting outside

Often, just a few minutes outside each day is all that is needed to improve your mood. Even gentle walking can release endorphins which reduce feelings of stress and pain.

Being outdoors can also help you feel freer and more grounded. Being connected to nature and your local community can help to refuel you and take your mind off your diagnosis, even for a short time.

While hiking in the hills is a great way to spend a day, even a walk around your local park, woods or neighbourhood could help bring some calm to your life. If you are in active treatment, speak with your doctor about how long you can spend in the sun.



Eating well

Depending on your situation, you might not be able to eat and drink what you want or used to, or not eat as much. By eating a balanced diet, you can make sure you are getting the nutrients that your body needs. This generally means eating unprocessed foods that are rich in whole grains, vegetables, fruits, beans, nuts, and lean proteins and reducing foods and beverages that are high in saturated fats, salt, sugar, caffeine, and alcohol. Please note that this doesn't mean you can't have a treat!

This can be tricky as you might want an instant energy hit or comfort food, but there are lots of recipes online or meal delivery services to help boost you with nutritious options. Adding more vegetables to what you normally make is a great way to begin. If you like a goal, aim for at least half your plate to be vegetables or salad.

Some of the common diet problems people with chronic cancer face are constipation, diarrhoea and dehydration, 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, or dairy-free diets, or the benefits of 'eating raw', or fasting. While some of these may make you feel like you're in control, there is very limited research to show it can affect tumour growth or progression of cancers. You should speak with your doctor before making any major changes to your diet.

Managing pain

Pain can affect everything from your sleep and appetite to the simplest tasks in your daily routine. There are many reasons why you might experience pain: The cancer itself can press on bones or organs, causing discomfort. Pain can also be a symptom of infection. Certain treatments can have pain as a side effect. Some medications may also cause discomfort. Emotional factors like stress, fatigue, and low mood can also increase the intensity of pain.

It can be useful to keep a pain diary to track and understand both your pain and how you are feeling emotionally. This information may be useful for your clinical team to consider when planning treatment. This could include surgical or medical treatments such as nerve blocks, radiotherapy, or simply over-the-counter drugs.

Complementary therapies

Your conventional medical treatments can be supported by complementary therapies to help you relax, improve your sleep, or provide pain relief. This can include acupuncture, reflexology, tapping, yoga, art therapy, massage, talking therapies, and cold water therapy. Some hospitals even have free or discounted therapists on site.

Complementary therapies can be used alongside conventional cancer treatment. You may hear the term used interchangeably with 'alternative therapies' but the two are different and alternative therapies are often used in place of conventional treatment.



Emma: “It can be tricky to manage people’s expectations of you and your own guilt around not being able to work or be there for people to the best of your ability. Fatigue goes up and down and you shouldn’t have to justify why you can’t concentrate.”

Reducing scanxiety

Knowing that you have scans or tests. (so those who don’t have scans don’t feel like they can’t have scanxiety!) coming up can play on your mind. This is often termed ‘scanxiety’ and the first step to managing this is acknowledging that waiting for results is hard. If you feel able to, talk to someone about how you feel. This may be a friend or family member but you may also find it useful to speak to someone who has been through this too. Shine’s chronic cancer group can be a good way to connect with others in a similar position.

To help you manage the anxiety, you can ask your team when and where the scan or test will happen, when you are likely to get the results, and how you will be informed. Sometimes there are workarounds and the team can book a follow-up appointment sooner or, in some cases, share the results over the phone or via an online platform. If you’re worried

about the scan or test itself, tell your care team so they can help you plan ways to be more comfortable. Afterwards, try to do something nice for yourself, even if it is just going for a walk, a drink, or a meal.

Relaxation exercises such as deep breathing, stretching and meditation, can help you manage your scanxiety. Consider calming activities for the hospital too: listen to a podcast, read a book, take something creative in, or consider taking someone with you. Remember that distraction can be very useful during your wait for results; if you feel up to planning a meet up with friends or even just a box set binge, go for it.

When you get your results, schedule time to go over them. If it is in person, try to arrange a time that works for you if possible. Consider also whether you want to take someone with you, as it can be helpful to have someone to take notes and ask any questions you may forget about.

Managing fatigue

Cancer-related fatigue is not like tiredness; it is a persistent, draining exhaustion which affects both your body and mind. Fatigue is a common cancer symptom that can prevent you from functioning normally. It is often not relieved by rest and can lead to insomnia. It can be particularly hard to deal with when you have a chronic cancer and no ‘end point’ in sight.

Some of our community tell us that reminders and lists can help them work around the fatigue, such as appointment and medication prompts, shopping and meal planning, and social activity reminders. Though it may seem counter-intuitive, light exercise such as walking can also help, as can eating easy but nourishing foods.

It can be difficult to explain fatigue to people who haven’t experienced it and this can leave you feeling frustrated and isolated, as you don’t feel validated. Don’t put yourself under unnecessary pressure by trying to reason with people or feel guilty for not being able to do everything that you want to do. Acknowledge that whether you are on or off treatment, you can still have fatigue, and that is ok.





 **Hormones are the chemical messengers that coordinate different functions in your body.**

Hormone disruption

Cancer and your treatment can have an impact on your hormones, changing your metabolism, sleep-wake cycles, sexual functions, reproduction, and other bodily processes. If you take gender-affirming hormones, you should speak to your cancer team in case they want to pause or reduce them during treatment.

Menopause

Menopause is usually a natural part of ageing for women as the production of oestrogen and progesterone slows down. Periods gradually stop and some women experience a range of uncomfortable symptoms. While it usually occurs between 45 and 55 years of age, some cancer treatments – such as chemotherapy, hormone therapy, surgery to remove both ovaries, or radiotherapy to the pelvis – can put you into early or premature menopause. In some cases, the menopause will only be temporary, but for others it will be permanent. It's always worth asking your doctor specifically about whether or not your treatment is likely to disrupt your hormones. You may want to find out if there is a menopause clinic you can be referred to or other support available.

Changes in hormone levels could cause no issues at all or it could lead to symptoms including hot flushes,

difficulty sleeping, pain and weight gain. 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. However, for some cancer types, HRT is not recommended.

To some, an early menopause can be 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 if you need extra support. Speak with your healthcare team to see what support they can offer, have a listen to our podcast [Not Your Grandma's Cancer Show](#), which has several in-depth episodes on menopause or have a look at our [Menopause After Cancer Facebook group](#) for people going through similar experiences.

Managing female hormonal changes

There are ways to reduce symptoms and your doctor can also prescribe drugs or treatments that can help. Some techniques include:

For hot flushes, wearing natural fabrics, keeping the room temperature cool, reducing caffeine, and eating a plant-based or Mediterranean diet could help. If you regularly eat spicy food and have hot flushes, try milder spices to see if that helps with your symptoms.

If you experience vaginal dryness, cystitis, or pain during sex, your GP can prescribe topical oestrogen which does not enter the bloodstream and is not considered HRT. To reduce discomfort, vaginal moisturisers and good quality lubricants can also be useful.

Sleep can also become disturbed, so try physical exercise in the day rather than the evening, reducing caffeine intake, and keeping your bedroom cool for sleeping.

Stress can exacerbate and increase the effects of menopause. Relaxation techniques and therapies such as massage and acupuncture can help reduce and manage symptoms.



Male hormones

as women, just at different levels and affecting the body in different ways. They play a crucial role in many aspects of men's health including building muscle and bone mass, reproduction, and helping to protect the central nervous system and reduce anxiety. Some treatments, including hormone therapy, chemotherapy and stem cell treatment, can lower the level of hormones the body produces. This may lead to tiredness, low mood, hot flushes, hair loss, weight gain, difficulties in getting an erection, or a reduced sex drive.

Speak to your consultant before you start treatment to see what changes you could see and how to manage them. If you notice any symptoms after your treatment, speak to your team about checking your hormone levels. If your levels have been affected, your medical team will be able to recommend solutions such as testosterone replacement therapy.



Impact on fertility

It can be hard to predict exactly what effect your cancer or treatment will have on your fertility, but if having children is important to you, you should find out as much as you can when you are first diagnosed.

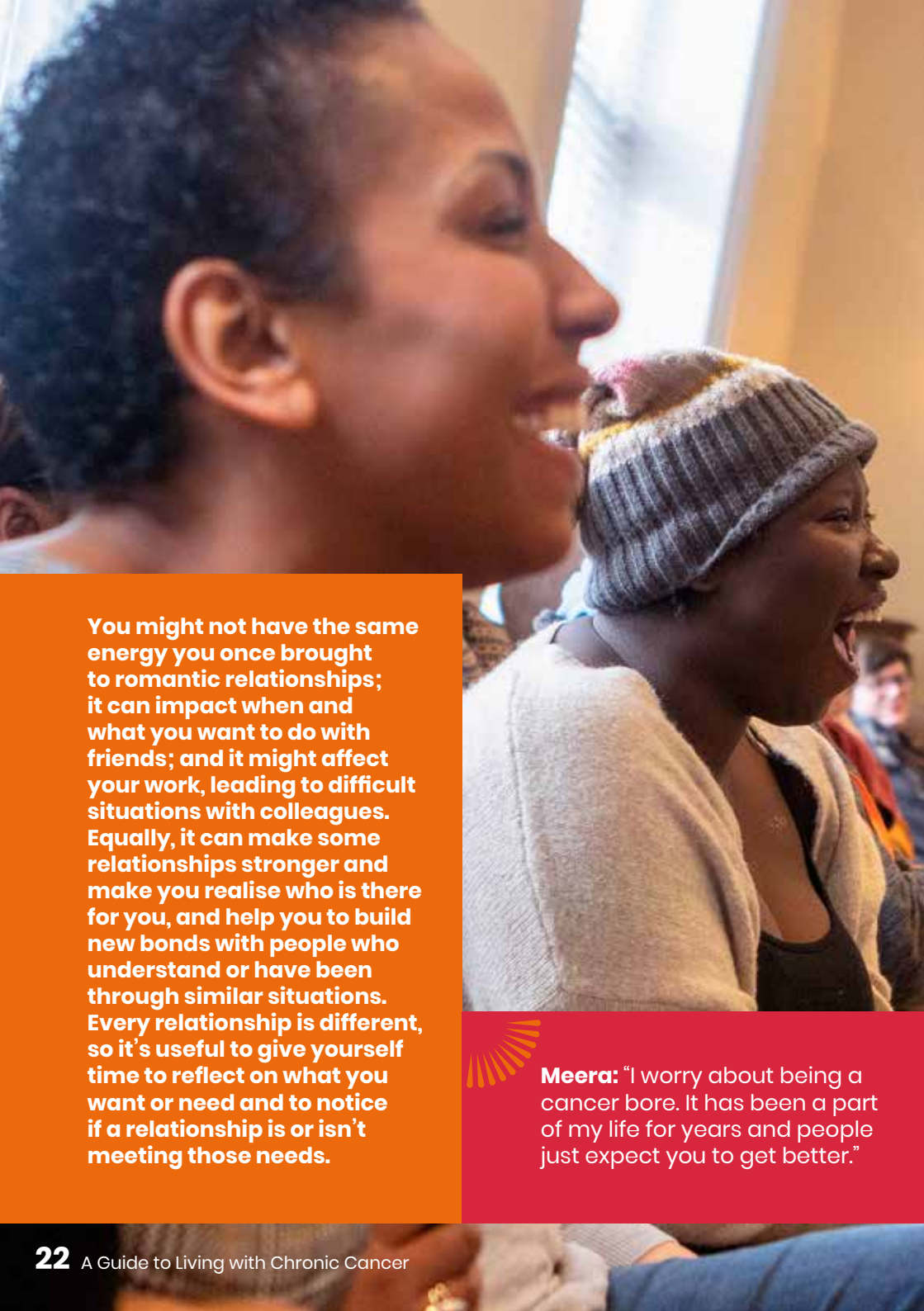
This might include information about how your cancer might affect your fertility as well as fertility preservation before starting treatment. For women, some cancer treatment can cause damage to the eggs, womb, cervix or hormone production, or start an early menopause, and for men, it could be that your sperm production slows down or stops, or you could have problems maintaining an erection. Women may also want to find out about whether a pregnancy could impact on their cancer.

Bear in mind some treatments for chronic cancers are relatively new and there will be few studies on the way in which a pregnancy, treatment, and cancer may interact. There are a number of choices in how to become a parent and what's most important is to explore the decision which is right for you. Trying to conceive naturally may be an option or going the direction of IVF, donors, surrogacy or adoption may be preferable.

In terms of adoption, every case is individual and your cancer diagnosis does not necessarily prevent you from being accepted, assessed and approved as an adoptive parent. However adoption services will want to ensure, as much as possible, that any adopter can parent their child into adulthood and beyond. Assessments for adoption usually include a health assessment, so you will need to be clear about your health status and may want to discuss this in advance with your GP and your treating consultant.

Speak to your GP or consultant about your fertility or ask for a referral to a fertility specialist.

If you are considering adoption, Parents And Children Together (PACT) is an independent adoption charity and family support provider. We also have a [fertility section](#) on our website with links to resources.



You might not have the same energy you once brought to romantic relationships; it can impact when and what you want to do with friends; and it might affect your work, leading to difficult situations with colleagues. Equally, it can make some relationships stronger and make you realise who is there for you, and help you to build new bonds with people who understand or have been through similar situations. Every relationship is different, so it's useful to give yourself time to reflect on what you want or need and to notice if a relationship is or isn't meeting those needs.

Meera: "I worry about being a cancer bore. It has been a part of my life for years and people just expect you to get better."

Building and maintaining relationships

Dealing with cancer treatments, side effects, and the upheaval of your life can affect the relationships with people around you.

Friends and family

Those who are closest to you to may act in different ways – they may be supportive and offer help and want to listen, or they may want to bury their head in the sand or disappear completely. It can be hard when others behave in ways you weren't expecting. If you feel able, talking about how you feel and explaining what you are going through can help you to understand each other.

Making new friends adds a new set of challenges as it can be hard to know when and how to describe your chronic cancer. Explaining that you live with cancer and what that means can feel difficult, though do remember that you are not under any pressure to reveal information that you don't want to. Some friends – new and old – may also have difficult questions, but it's up to you to choose how much information you want to offer. It's perfectly acceptable to tell people that you don't want

to discuss your cancer, or parts of your treatment. It may be useful to rehearse how to explain your cancer in social situations, whether with another person or in front of the mirror.

It can also be hard to maintain your social life, for instance if you are worried about infection, are fatigued, or are in the middle of treatment. Taking time for yourself and looking after your health is important and there are other ways to connect with people – keeping in touch virtually, sharing news with a 'spokesperson' friend to preserve your energy, or pencilling in dates when you think you might be feeling better with the proviso that you may have to cancel. To avoid sending dozens of messages, some people set up a single WhatsApp group where they can share information (and also mute the group if needed!).



Emma: “It is difficult to date – when do you disclose it and how much do you say? It is such a huge thing as you’re talking about an unknown future.”

Partners

It is often at times of crisis that relationships are tested. Stress levels can build up, as daily routines are turned upside down by appointments and tests, as well as the knowledge that cancer is going to be a part of your life from now on. Relationships might experience a change in roles and responsibilities. There may be different physical and emotional needs and all of these shifts can impact intimacy and sex.

For some couples, facing the challenges of cancer together strengthens their relationship. For others, the strain of cancer can create new problems or worsen existing ones. Shine’s research has also indicated that only about 8% of partners ever get asked how they’re feeling although their lives have also been affected.

As your future has some uncertainties, it can help to evaluate your priorities and work together on new goals for your future. It could be sometimes as simple as enjoying a meal out once a month, depending on levels of fatigue, to give yourself some time alone.

If your partner is looking for support, Shine has a Plus Ones programme which might be useful. This includes an online six-week programme called Plus Ones Circles.





Claire: “Cancer has made me less tolerant of people and things. Some people aren’t supportive and you are better off without them.”

Dating

Dating can be intimidating at the best of times, but when you have chronic cancer you can worry about when to tell dates, if they will be put off, or how you might feel navigating a relationship with cancer. You may now feel a different level of confidence. If you want to date or find a partner, having cancer doesn’t need to get in the way. Lots of people in our community do go out on dates and have found someone special after being diagnosed.

When you feel the time is right to tell a new partner, they may respond in a number of ways. They may initially be shocked and take a little time to adjust to this news. They may have their own anxieties and fears around cancer and what it means to them. Or they may be accepting and recognise that your cancer is part of who you are.

Building your social connections and support system can also help you to feel content and loved in other ways so there is not as much pressure on dating.

Sex

Your cancer or treatment could have changed the way you feel about yourself or thrown in obstacles such as erectile dysfunction, sexual

pain, or anxiety. You may see physical or emotional changes to your body that can make you feel low or ‘unsexy’. Whatever you are feeling, you’re not alone.

If you are in a relationship, this can cause issues as your partner may feel rejected or feel that the relationship has changed more than expected. If you are dating, it can be overwhelming to consider how to explain any changes to your body to a new person. Communicating these with the other person can help you both to be on the same page, and if they are uncomfortable in any way, it is best to know beforehand.

Finding new ways of continuing to be intimate with your partner may help you to adjust to the physical and emotional changes that happen. You might consider specialist help if there are sexual issues you want to address, for example with a relationship or psychosexual counsellor. Shine also has some [useful resources](#) on intimacy, including podcasts. You will need contraception if you’re having sex while receiving treatment. Speak to your consultant if you have any questions or worries.



Looking after children

A parent's longing to ensure that their child is happy can sometimes lead to holding things back that might hurt or worry them. Many parents in Shine find that honesty is usually the best approach when speaking to children.

Children don't need to know every detail, but to know enough that they understand the situation and how it might affect them. Your child or children might receive support from other family members, teachers or babysitters, so including your children's support networks can be useful as well.

Children of different ages will cope with a parent having cancer in slightly 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 therapy to help them to make sense

of your chronic cancer and what it means for you and the family.

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.

Things that may help

- Speak to your consultant or clinical nurse specialist about things such as the timing of appointments.
- If you are working or studying, see what support your employer or tutor can provide in terms of flexible working.
- If you have a partner, talk to them about shifting responsibilities while you're going through a difficult time. If possible, ask friends or family to help with practical things like school drop-offs, meal preparation, or cleaning.
- Contact community groups such as social services, faith groups, charities, or schools, as there may be people who can visit your home to help with childcare.
- Depending on their age, you could speak to your children about helping around the house. Children often want to feel helpful and this can also help them feel more in control of the situation.

You can find more information about parenting and supporting children at [Parenting with Cancer](#) or [Mummy's Star](#)



Work and study



Depending on your job or choice of studies, it can help you to have a routine, to think about something else, to develop your career, or, of course, to bring in money. However, your ability to participate may be affected, particularly if you have fatigue, drowsiness, memory problems, or physical issues. There is support to help you decide how to go about your work and studies in a way that allows for your treatment and limitations.



Your rights in work

We all have different experiences with treatment and the impact it has on our ability to work. Some people are able to maintain a routine and a sense of normality, whereas others may feel too tired, in pain, numb or nauseous to work.

It is important to know that you are covered by the Equality Act 2010 and the Disability Discrimination Act, and with that comes additional support and legal backing. 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.

At work, you should have access to disability leave, statutory sick pay, occupational sick pay, pension rights and work-related private medical insurance, if provided. 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, and you may also find it useful to speak



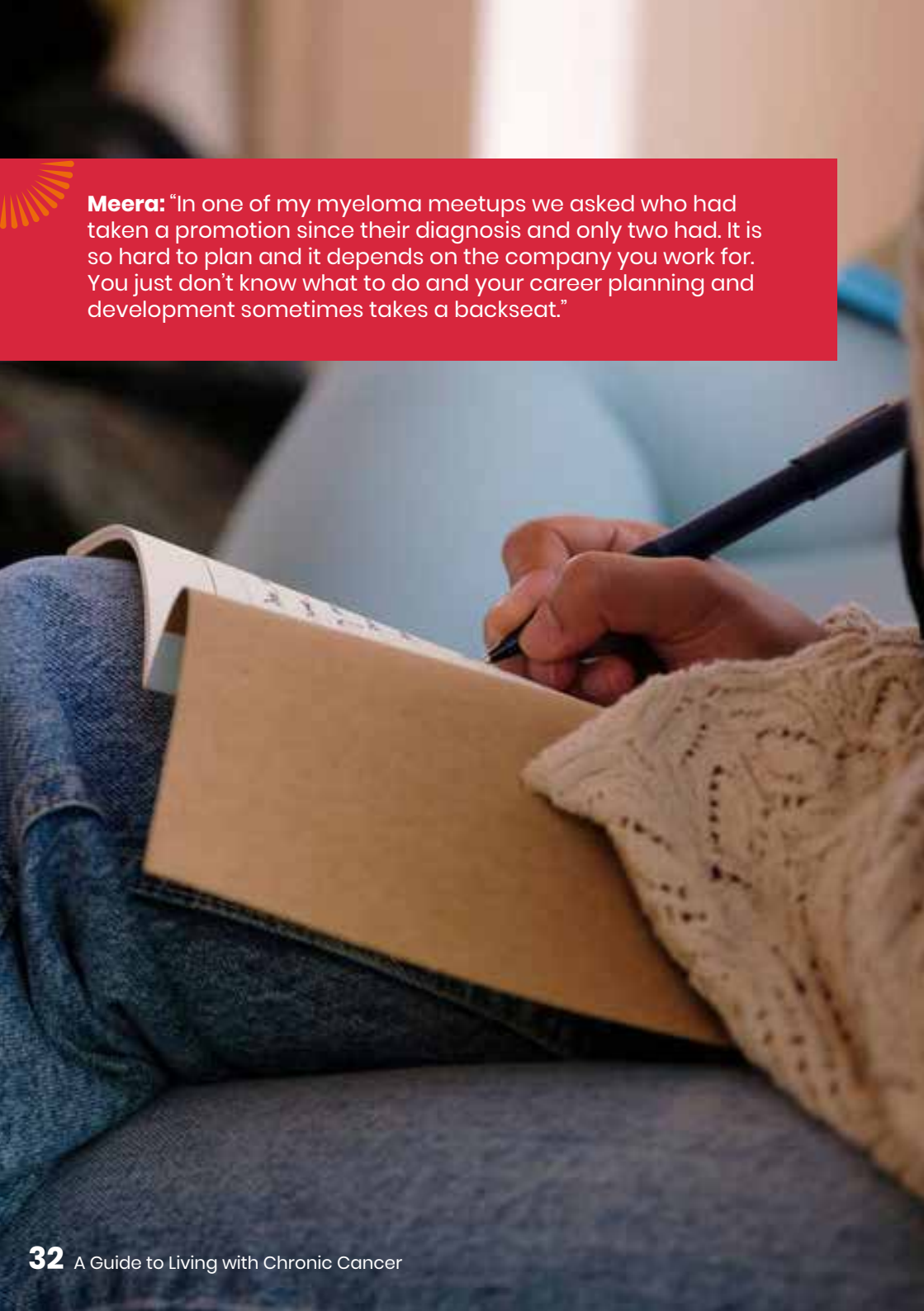
with [Citizens Advice](https://www.equalityadvisoryservice.com) or Equality Advisory Support Service for free, confidential advice. [equalityadvisoryservice.com](https://www.equalityadvisoryservice.com)

Study

Continuing or starting “a course” or “to study” might be more difficult to manage at times, but you should have the same opportunities and chances of doing well as your peers. We all have different experiences with treatment and the impact it has on our ability to be productive. Some people are able to maintain a routine and a sense of normality, while others may feel like they could study while dealing with treatment or side effects if they are given some accommodations.

As you automatically meet the definition of ‘disabled’ (whether you feel that way or not), education and training

providers have a duty not to discriminate against you. Start by contacting your institution's disability service to see how they can support you with your specific needs. They should make reasonable adjustments, for example, more time for assignments if you have fatigue, use of a room to take breaks, or a car parking space. You might want a more formal needs assessment, particularly if you decide to apply for Disabled Students' Allowance (DSA). DSA can help pay for specialist equipment such as a digital recorder for recording lectures, and extra travel costs.

A close-up photograph of a person's hand holding a black pen, writing on a piece of lined paper. The paper is resting on a light-colored, textured surface, possibly a table or desk. The background is blurred, showing a person's arm and a blue garment.

Meera: “In one of my myeloma meetups we asked who had taken a promotion since their diagnosis and only two had. It is so hard to plan and it depends on the company you work for. You just don’t know what to do and your career planning and development sometimes takes a backseat.”

Money

Having cancer can bring extra costs such as heating bills, hospital parking, travel costs, and child or pet care while you have treatment. If you have to stop or reduce your work, it can be difficult to manage your financial commitments such as rent, mortgage, or utility bills.

Sickness benefits

These are benefits to provide you with a basic income to live on while you are off sick from work – whether you were employed, self-employed, or looking for work when you were diagnosed. These include statutory sick pay (SSP) from your employer, and if you are self-employed you may be able to get Employment and Support Allowance (ESA) or Universal Credit (UC).

Help from your local council or utility services

There are a number of ways you may be able to get help from your local council, such as council tax support and reduction, housing benefits, or Discretionary Housing Payments for those on a low income.

It is also worth contacting your service providers – such as gas, electric, water and internet – to see if they can reduce costs or offer delayed payments.

Disability benefits

You may be able to get extra help in addition to all other benefits, at any stage of your illness and regardless of any other income, savings, or your National Insurance record.

These disability benefits are for extra difficulties for people with a long-term illness or disability. This is regardless of whether these stop you from working or not, so these can be useful both during treatment and on return to work.

Even if you are not struggling financially, it is still worth contacting these providers as they can add you to their priority registers so you get more help in the event of, for example, a power cut.



Financial advice

If you are concerned about the financial implications of your cancer diagnosis, you can speak to a benefits advisor through organisations including [Maggie's](#) or [Macmillan](#).

Insurance

It can be challenging to obtain insurance once you have been diagnosed, but it is worth looking at what insurance you currently have, if any, to see if it could help financially to make a claim. For instance, critical illness insurance pays out a single lump sum if you are diagnosed with a serious illness covered by the policy. If you want to buy insurance, such as life insurance, the insurer may decide not to accept your application because of your diagnosis or they may ask you to pay a higher premium, or apply an excess or exclusion.

Pensions

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, but this will depend on the rules of your particular 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's Financial Team, MoneyHelper or Citizens Advice or you might want to speak to a financial adviser through Unbiased.

Special treats and support

You should also check out [the Willow Foundation](#), [Osborne Trust](#) and [Something to Look Forward To](#) for help with special treats.

Emma: "I'm fortunate to have income protection for five years through my job, so I would get 70% pay, but what happens at the end of it? Do I make the most of being well and consider early medical retirement?"



Questions that could be helpful

Our chronic cancer community wanted to share what questions they wish they'd asked their healthcare team when they received their diagnosis:

- **What services and support can you offer me, such as counselling, menopause clinics, fertility specialists or LGBTQ+ networks?**
- **Who can help me navigate the NHS – how to book appointments, contact my team, or make sure that things are happening on time?**
- **What are my treatment choices? Which do you recommend for me and why?**
- **How can I manage the symptoms of my 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?**
- **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?**
- **Do you have any support or experts who can help to manage fatigue?**

You've found Shine!

We're so glad you're here reading this because it means you've already found Shine. One of the things we hear all the time is: "I wish I'd found Shine when I was newly diagnosed as it's made the biggest difference."

We know everyone is different which is why we offer loads of different types of support. You might want to go to a meetup specifically for living with chronic cancer or join some of our activities for people with all types of cancer.

Chronic cancer meetups

Regular informal, virtual meetups to share experiences and discuss topics specific to those with chronic cancer.



Here are just some of the things we offer...

Shine Networks

We have networks across the UK who meet up regularly for chats, coffee, and evenings out.

Online Programmes

While we don't have a separate programme for people with chronic cancer, we have had people with chronic cancer join many of our programmes. Drop us an email at hi@shinecancersupport.org and we can chat about what's right for you.

Shine Connect

The UK's only conference for young adults with a cancer diagnosis, held annual both in person and online.

Shine Camp

A weekend camping trip in Dorset for up to 100 people. Held every year, usually in July or August. You can find the meetups and other events on the [event calendar](#).

Plus Ones

Our Plus Ones Circles programme gives partners of young adults with cancer the chance to be part of a small online group of people having similar experiences.

Podcast

Our 'Not Your Grandma's Cancer' show podcast covers a huge range of topics and has some specific episodes on living with chronic cancer.

Personal Experiences

Many members of the Shine community have shared their experiences with cancer. You can filter based on age and cancer type.

Book Club

Our virtual book club meets every five or six weeks to discuss a chosen book.



Fundraising for Shine

As a small charity, we rely on the donations we receive to continue to deliver our services and events. If you or someone you know is looking for a charity to raise donations for at your next mountain trek or 10k run, why not suggest Shine? No matter how big or small the event, we are here to support you and cheer you on.

Find out how to get involved by visiting our [website](#).

Volunteering opportunities

We are always on the lookout for volunteers to run our networks so that we can support more young adults with a cancer diagnosis. There are a mixture of in-person and remote roles, with various time commitments, for those with experience of a cancer diagnosis and those without.

Find out more about these roles on our [website](#) or email volunteering@shinecancersupport.org



Keep in touch

Thank you for reading our booklet for young people living with chronic cancer. We have a ready-made community here when you feel ready. If you'd like to dip your toe into cancer support without speaking to anyone, take a listen of our podcast.

Please do get in touch with us if you need specific support or services. Find out more information by checking out our website, following us on social media, or dropping us an email.

hi@shinecancersupport.org

www.shinecancersupport.org



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