

Live your Life

Living with and beyond lymphoma

Module 2: The emotional
impact of lymphoma





I didn't want to go through the details of my illness with friends and family on a daily basis. I wrote a blog, so that anyone who wanted to know how things were going could read it. I found writing the blog really therapeutic. It was a way of getting a lot of anger and fear off my chest and helped me get through the whole process.

Kat

Module 2:

The emotional impact of lymphoma

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Notes

You can use this space to make any notes from module 2 of the Live your Life workshop.



Action plan to help me live well.

Action	Resources	How often
Try a stress-relieving technique such as mindfulness	Listen to a mindfulness podcast on the Mental Health Foundation's website. Download a mindfulness app such as <i>Calm</i> , <i>Headspace</i> or <i>Smiling Mind</i> .	Twice weekly



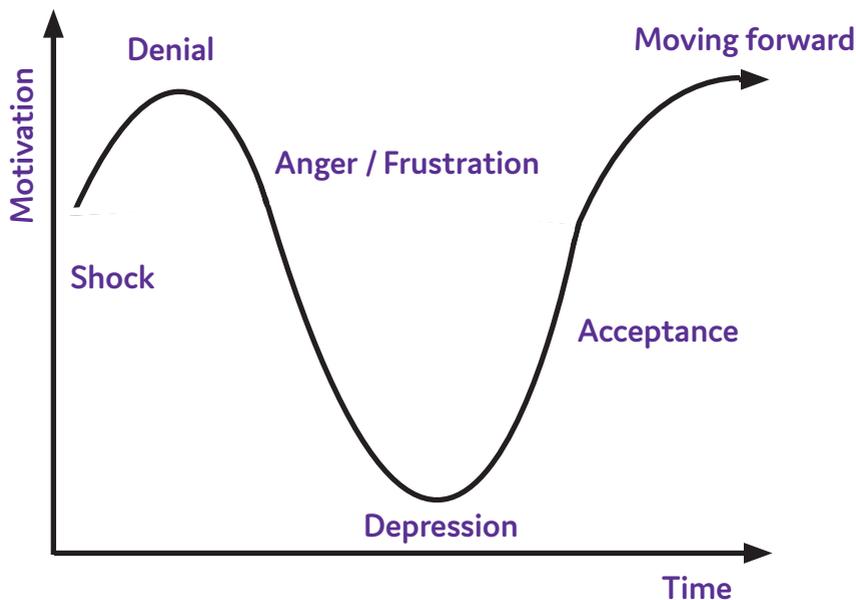
You could use this space to list anyone (health professionals, organisations, family and friends) to contact if you're concerned about how you're coping or would like some support.

Name	Contact details

Your feelings

When you or someone you love has been diagnosed with lymphoma, you are likely to go through many thoughts and emotions. We cover some of these in this section. However, you won't necessarily feel any or all of these, nor in a particular order or at set times. You might also go between feelings more than once. This is entirely natural and there is support available.

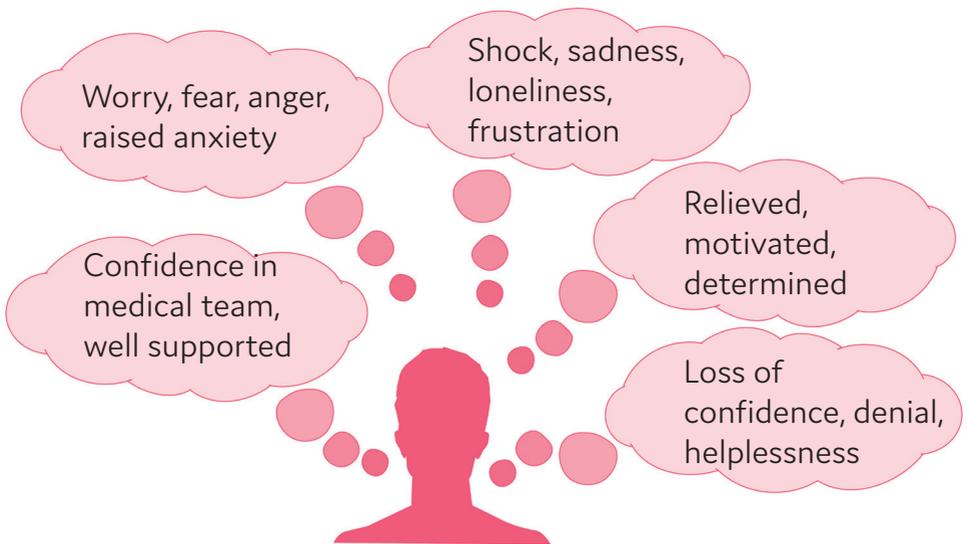
Some people find it helpful to see feelings noted in a diagram, for example, a change curve. This represents the ongoing adaptation that comes with living with lymphoma.



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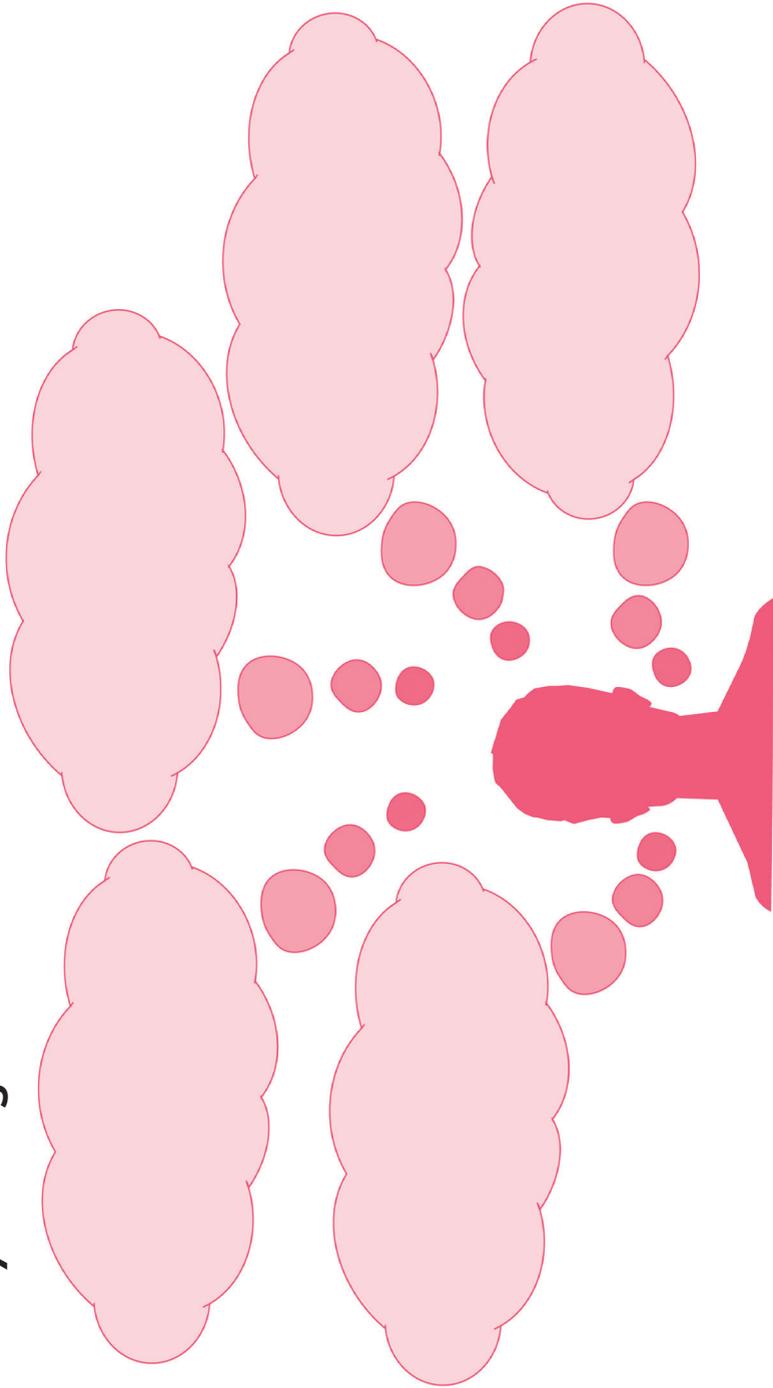
While there isn't a 'normal' way to feel, we've noted some of the emotions you might experience below. You might experience negative feelings, or you might have positive emotions, or a combination of both.

There's space on the next page for you to note feelings you've experienced since your diagnosis.



You might like to use the space on the next page to note down your feelings. You could mark with a highlighter or star the ones that have been particularly powerful.

My feelings





Some people track their mood in a diary. This can help to identify any patterns, such as triggers to difficult feelings and things that help you.

When	What was happening	Mood rating (0 = worst, 10 = best)	What did or might help?
16 May	Day before blood tests	3	<ul style="list-style-type: none">• Talking to friends.• Going for a walk.



There are lots of mood tracker apps available.

- **Mind, the mental health charity, has a list of apps for mental wellbeing. Search 'mental health apps' on their website at mind.org.uk**

Low mood and depression

Living with lymphoma can significantly affect your mood. You might feel a sense of loss for the life you had before you were diagnosed, or for plans you'd made that you are now reconsidering. These feelings of loss are a type of grief and might trigger memories of other losses you've had. You might also feel sad for your family and friends, knowing that they are also coping with difficult feelings.

A diagnosis of lymphoma can also affect your sense of control. It might seem that you no longer have influence over things that are 'happening' to you; that you have lots of appointments that tell you when and where you need to be, without fully understanding them. For some people, this leads to a sense of hopelessness and low mood.

It's natural to feel low from time to time, and it can take a while to process all the changes that are happening in your life. If you feel very low for more than a couple of weeks and it affects your day-to-day life, it could be a sign of depression.

Depression can affect people in different ways. For example, you might feel:

- anxious, sad or 'empty'
- hopeless, helpless and pessimistic
- guilty or worthless
- a loss of interest in activities you once enjoyed
- unable to concentrate or remember things
- difficulty in making decisions
- as though you want to harm yourself, which could include thoughts of ending your life.

You might experience physical symptoms such as aches, pains, a change in appetite, sleeping more or less than usual, slow movement and speech, or loss of sex drive (libido).

If you have been affected by depression in the past, you might be more likely to do so again after a diagnosis of lymphoma.

Experiencing depression doesn't mean that it will last forever – there is support available, which might include a combination of approaches such as talking therapy, mindfulness and, for some people, medication.

Speak to your clinical nurse specialist or GP if you think you might be affected by depression. Getting help early can help to lessen the risk of developing more severe depression.



- **For more information about depression, visit [mind.org.uk/Depression](https://www.mind.org.uk/Depression)**
- **If you're having a difficult time, Samaritans are available 24/7 and 365 days a year. Call 116 123.**
- **You can also contact CALM, if you need to talk. Their helpline is available 5pm until midnight, 365 days a year on 0800 58 58 58.**
- **SHOUT is a free and confidential text line, available 24/7 – text 85258.**

Coping with difficult feelings

People find different ways of coping with difficult feelings and circumstances. While none of these can change your situation, they can help to make it more manageable.



Tips for processing difficult feelings

- **Talk to someone about how you're feeling** such as a family member or friend, our helpline or a counsellor.
- **Write about your feelings** in a journal, diary or private blog. You could write a letter to yourself about how you feel, then a response to yourself with tips and advice, as if you're writing to a friend. Another idea is to keep a private vlog (video blog).
- **Express yourself creatively** for example through music, drawing or painting.

Wellbeing plans



During times of high stress, low mood or upset, it can be hard to remember what helps you and who is there to offer support. You might find it helpful to note these things down, in order to make a wellbeing plan. Keep this list somewhere that's easy to find. You could print a copy or save a photo of it on your phone. This can make it easier to draw on during challenging times.

What's happening now?

How I hit the pause and reset button

What helps to calm me or lift my mood

The people who help or support me

Some helpful contact numbers or websites

Things that recharge me

Stress

Living with lymphoma can bring a great deal of stress, which can have a range of physical and psychological effects. For example, you might feel anxious, have difficulty concentrating or feel irritable. You might have difficulties relaxing or sleeping. Stress can also cause increased heart rate, headaches, muscle tension, dizziness, loss of appetite and nausea.

There's no evidence that stress can cause or worsen cancer. However, it's important to find ways of managing it, for your wider physical and mental wellbeing. Taking care of your health by eating well, exercising and getting enough rest can all help.



Tips for managing stress

Different people find different things help with managing stress. You could try:

- relaxation techniques like breathing exercises, meditation or mindfulness – you could try a meditation app to help with these
- planning something to look forward to, such as having coffee with a friend or going on a day trip
- a complementary therapy, such as massage, acupuncture or aromatherapy
- taking exercise to help let out feelings of stress
- taking a problem-focussed approach (see below).

Problem-focussed strategies

Consider what the sources of your stress (stressors) are and which of them you can do something about.

- Note down your stressors in the thought bubbles below.
- Consider which of them you can do something about and come up with a plan.



- The NHS website has a section on mental health at [nhs.uk/mental-health](https://www.nhs.uk/mental-health) to help you manage mild to moderate stress and anxiety. It offers practical information and interactive tools to support you.
- Living life to the full is available at [littf.com](https://www.lifetofull.com) and offers free online courses to help with low mood, stress and building resilience.



Use the space below to note down your ideas to help you deal with your stressors.

Stressor	Strategy and resources
Childcare during treatment	• Ask family, friends and neighbours to help with school drop-offs/pick-ups.

Relationships

There are likely to be changes in some of your relationships after a diagnosis of lymphoma. Some interactions might feel strained, while others grow stronger.

One of the challenges we hear about from people affected by lymphoma is that others seem to expect them to 'return to normal' soon after treatment. This can feel hurtful and insensitive – you might feel frustrated and as though they have no idea of the realities of all you've been through. We also hear that others seem to avoid conversation. This is probably through fear of saying something upsetting, but it can bring a sense of loss and isolation. It might help to try to create your new normal together with friends and family members.

While each relationship is unique, communication is always important in maintaining good relationships.

'I' statements

At times of high emotion, 'I' statements can be a helpful way to express yourself. They focus on you and your feelings, as opposed to the other person's behaviours and can lower the risk of angry, hurt or defensive responses and the perception of blame. When using 'I' statements, think about how you feel and why, and how you'd like things to be different – you might also have ideas for how this could happen.



You can use the space below to try out using 'I' statements.

Statement	Rephrased using an 'I' statement
It was embarrassing when you told our friends I couldn't see them.	<ul style="list-style-type: none">• I was upset you'd told our friends I wasn't feeling well enough to see them. I was worried they might not contact me so much in the future.• We could let them know I appreciate their care and that I'll contact them when I have more energy.



Tips for talking to your partner

- Be honest about how you feel.
- Explain what you'd like and need to help them understand how they can support you.
- Although it might feel awkward at first, try to talk honestly about physical closeness and sexual intimacy.

Tips for talking to children

- Trust your intuition – you know your child.
- Be as specific and honest as possible, and allow them to ask questions.
- Use explanations they can understand.
- Use real words such as 'cancer' to help them understand what is happening and reduce the risk of misinterpreting.
- Prepare them for any changes to their day-to-day life. As far as possible, explain these to them, with reasons, in advance of them happening.

Tips for talking to friends and colleagues

- Let people know how they can support you.
- Reassure them they don't need to say the 'right thing'.
- If you'd find it helpful, ask someone to be a key contact who can share information with others on your behalf.
- Consider using social media or group emails to update a group of people quickly and easily.
- You could signpost people to the Lymphoma Action website so they can find out more for themselves.



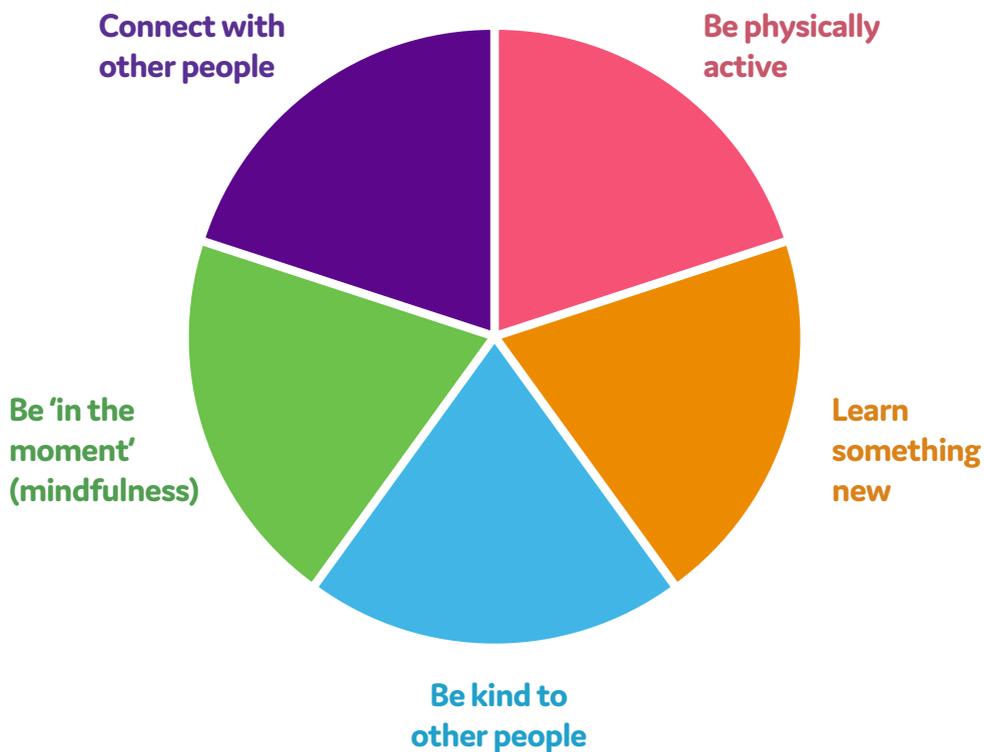
- **Search 'communication' at relate.org.uk for more communication tips.**
- **Macmillan Cancer Support has a book called *Talking about cancer*, which aims to help you talk about your cancer and understand other people's responses: search 'talking about cancer' on macmillan.org.uk**

Emotional wellbeing

Emotional wellbeing is about how you feel and how you feel you're coping with day-to-day life. It includes:

- confidence and self-esteem
- contentment and enjoyment
- your sense of connection with the world and people around you
- productivity
- dealing with stress and anxiety.

The NHS 5 steps to mental wellbeing



- Search '5 steps to mental wellbeing' at [nhs.uk/live-well](https://www.nhs.uk/live-well) to find out more about these areas.
- The Mind website also has tips for mental wellbeing (see page 115).

'Happy' or 'feel good' hormones

You might have heard of 'happy hormones', such as endorphins, serotonin, dopamine and oxytocin. These are chemicals your body naturally produces. They can help boost mood and reduce pain.

Some people find it easier than others to access these hormones. This depends on individual factors, such as early infancy and childhood experiences.

There are some natural ways of increasing your level of these hormones, including exercise, music, laughter, physical touch and closeness with the people you care about.

Mindfulness

Mindfulness is a type of meditation that encourages you to slow down and take note of your body and thoughts, as well as the world around you. Focusing on the present moment can lower the stress you feel in worrying about the future or going over the past. It encourages you to give your energy to the present day, which can improve your wellbeing and quality of life.

You can be more mindful in your everyday life just by slowing down and noticing things around you.



Tips for being mindful

- Pay attention to things like sounds, smells and the feeling of a fabric or breeze against your skin. You could take a 'mindful shower' – listen to the sound of the water, pay attention to the temperature of it and the feel of it on your skin.
- If your mind feels 'busy' or cluttered, try visualising thoughts leaving your mind to clear it.
- Label thoughts and feelings. Notice if and where you feel things in your body – for example, a tightness in your chest when you feel worried. Try to name the emotions that come with the feelings.



You can find out more about mindfulness and access free resources online. Search 'mindfulness' on the NHS website or on the Mental Health Foundation website.

Notes

Note some of the things you'd like to try to improve your mental wellbeing.



- We have an emotional wellbeing toolkit on our website, which includes guided mindfulness videos and downloadable resources.
See lymphoma-action.org.uk/emotional-toolkit
- The NHS website has a list of free mental health apps that you can download. Search 'mental health apps' at nhs.uk/live-well
- Visit Headspace at headspace.com to download a meditation app or sign up for free to access online meditation tools.
- Download the free *Smiling Mind* mindfulness app at smilingmind.com/au or search for their YouTube channel to watch a series of mindfulness videos.

Information and support

If you'd like to talk to someone about anything to do with lymphoma, get in touch.



Call our **Helpline** (freephone) Monday to Friday, 10am to 3pm, on 0808 808 5555. You can also use Live Chat on our website



Join one of our peer support services such as **Support Group, online support meeting** or **closed Facebook support group**. Find one at lymphoma-action.org.uk



Use our **Buddy Service** to share experiences with someone in a similar situation to you. Call our Helpline for details



Visit lymphoma-action.org.uk/TrialsLink to search for clinical trials that might be suitable for you



Check out our **YouTube channel** to watch personal stories and medical films

See our website for full details of our services. For our latest news and updates, follow us on social media:



@LymphomaAction



lymphoma_action



If you're interested in finding out more about any of the topics in this book, we have lots more information available on our website.

We also produce a number of books, which are available free of charge. In particular, you might find the following books helpful:

- *Introduction to lymphoma*
- *Living with and beyond lymphoma*
- *Active monitoring (watch and wait) for lymphoma*
- *Caring for someone who has lymphoma*

We also have some wellbeing videos available to watch. Search 'wellbeing videos' on our website.

Find our full range of books and information, including accessible information and Easy Reads, at lymphoma-action.org.uk/Books or call 0808 808 5555 for more information.

Useful organisations

We list some organisations below that you might find helpful. You can find more useful organisations on our website. If you don't find what you're looking for, please get in touch through our Helpline Services (see page 112).

Cancer Research UK has information about cancer, including about treatment and coping strategies.

www.cancerresearchuk.org

Citizens Advice provide free advice on matters such as housing, consumer, money and legal issues.

www.citizensadvice.org.uk

Every mind matters – NHS is a website from Public Health England with tips and advice for good mental health.

www.nhs.uk/every-mind-matters

GOV.UK is the UK government website. It outlines the financial benefits that people affected by cancer and their carers might be entitled to.

www.gov.uk

Look Good Feel Better helps people to manage the visible side effects of cancer treatment with free group and self-help skincare and make-up workshops

www.lookgoodfeelbetter.co.uk

Macmillan Benefits Advice Service offers financial advice, including welfare benefits, housing, work and debt to people with cancer and their carers.

Macmillan Cancer Support provides support for people affected by cancer from diagnosis through treatment and beyond.

www.macmillan.org.uk

Maggie's gives practical, emotional, financial and social support to people with cancer, their family and friends.

www.maggies.org

Mental Health Foundation has information about mental health, including resources designed to introduce techniques to support mental wellbeing.

www.mentalhealth.org.uk

Mind offers support and advice in relation to mental health. You can email their infoline at info@mind.org.uk or call on 0300 123 3393.

www.mind.org.uk

NHS website has health information.

www.nhs.uk

NHS inform is a health information service from NHS Scotland covering health and welfare, and including self-help resources that are free to access.

www.nhsinform.scot

Relate is the UK's largest provider of relationship support. Their services include information, workshops and counselling.
www.relate.org.uk

Samaritans offer emotional support to anyone who is struggling with difficult feelings. Their service runs 24 hours a day, all year round. Call 116 123 or email jo@samaritans.org
www.samaritans.org

Shine Cancer Support offers support for people in their 20s to 40s who have been diagnosed with cancer.
www.shinecancersupport.org

Shout offers support to anyone struggling to cope. They have a free and confidential text service available 24/7. Text 85258
www.giveusashout.org

Teenage Cancer Trust offers information and support for young people living with cancer and for their families.
www.teenagecancertrust.org

Working with Cancer helps employees, employers, the self-employed, job seekers, people who are self-employed, and carers to manage cancer and work.
www.workingwithcancer.co.uk

Young Lives vs Cancer offers clinical, emotional and practical support to children and young people with cancer, and to their families.
www.younglivesvscancer.org.uk

About our information

Our information is evidence-based, approved by experts and reviewed by users. By keeping up-to-date with latest developments, we ensure that our information stays relevant and reflects current practice. Learn more at lymphoma-action.org.uk/HealthInfo

How you can help us

Volunteering is at the heart of what we do. If you'd like to volunteer with us, visit lymphoma-action.org.uk/Volunteering

We continually strive to improve our resources and are interested in any feedback you might have. Please visit our website at lymphoma-action.org.uk/BookFeedback or email us at publications@lymphoma-action.org.uk with any comments. You can also call our Information and Support team on 0808 808 5555.

References

The full list of references is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619400 if you would like a copy.

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This book is part of Lymphoma Action's Live your Life peer-led, self-management workshops, but can also be used on its own. It is designed to support you to live well with and beyond your lymphoma, and includes lots of information, suggestions and places for you to write your own notes.

Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer. Our mission is to make sure no one faces lymphoma alone.



Helpline (freephone) **0808 808 5555** (Mon to Fri, 10am to 3pm)



Email **information@lymphoma-action.org.uk**



Visit **www.lymphoma-action.org.uk**



Live Chat via our website (Mon to Fri, 10am to 3pm)

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✓	Evidence-based
✓	Approved by experts
✓	Reviewed by users