

# Live your Life

Living with and beyond lymphoma  
Workbook to accompany workshops

Module 2: Coping with the  
emotional impact of lymphoma





**The Live your Life workshop provided a safe space for me to talk about my feelings with other people who understood how I was feeling and what I was going through – other people who speak the ‘lymphoma language’. Most important for me was being able to recognise and accept those feelings in a safe environment and discuss with others the different ways in which I could move on and find a new normal.**

Dorothy, diagnosed with follicular lymphoma





Chemotherapy and maintenance treatment took its impact on my energy and wellbeing. I found myself in an emotional, dark and lonely place. It was at this crucial point, some 18 months after my initial diagnosis, that I realised I needed to put my hand up and ask for help and could not fight this battle alone. In many ways I was grieving for the person I was before cancer.

Simon, diagnosed with stage 4 nodal marginal zone lymphoma

# Module 2: Coping with the emotional impact of lymphoma

This module is one of a series taken from our workbook 'Live your Life - living with and beyond lymphoma'.

There are five modules in total:

- Know your lymphoma
- Coping with the emotional aspects of lymphoma
- Exercise and staying active
- Diet and nutrition
- Practical aspects of living with lymphoma

You can download all of the modules, or the complete workbook, at [www.lymphoma-action.org.uk/lylworkbook](http://www.lymphoma-action.org.uk/lylworkbook)



**Use this space to transfer your notes from Module 2  
of your Live your Life workshop**



## Action plan

Action	How often
<i>Example: Try mindfulness</i>	<i>Once a week going forward</i>

If I am concerned about how I'm coping or need extra support, I will talk to:

Name (family, friend or health professional)	Contact details

## Your feelings

People respond differently to a diagnosis of lymphoma. It's not unusual to feel differently at various times, even within a single day. You might feel especially low at certain times during your experience of lymphoma, such as:

- when you are first diagnosed
- if you are put on active monitoring (watch and wait)
- at the start of treatment
- at the end of treatment
- before follow-up appointments
- if your lymphoma relapses.

There isn't a 'normal' way to feel, but some of the emotions you might experience are shown below.



Use the figure above to write down any other feelings you've experienced since having lymphoma.



It might be useful to track your mood on a chart or diary to help you identify things that make you feel worse and things that help you feel better.

Date	Mood score (1=worst; 10=best)	Comments
<i>Example: 16th May</i>	4	<i>Felt anxious after yesterday's blood tests</i>



- For more information on the emotional impact of living with lymphoma, search 'emotions' at [www.lymphoma-action.org.uk](http://www.lymphoma-action.org.uk) or call our Information and Support team on 0808 808 5555.
- Macmillan Cancer Support have a range of resources and forums on feelings after cancer. Search 'emotions' at [www.macmillan.org.uk](http://www.macmillan.org.uk)
- NHS Choices offers an online mood self-assessment tool. Search for it at [www.nhs.uk](http://www.nhs.uk)
- There are lots of different mood tracker apps available. Search for one that's suitable for your mobile phone.
- Find your nearest support group at [www.lymphoma-action.org.uk/SupportGroups](http://www.lymphoma-action.org.uk/SupportGroups). Your nurse specialist may also be able to direct you to cancer support groups in your area.
- Use our forum to connect with others affected by lymphoma: [www.lymphoma-action.org.uk/Forum](http://www.lymphoma-action.org.uk/Forum)

# Depression

Depression is a very common experience for people with lymphoma. It does not mean you are weak. You cannot just 'shake it off' or 'pull yourself together'; depression is an illness. It is normal to need support, just as you would for a physical illness.

Depression can affect people in different ways. You may feel:

- anxious, sad or 'empty'
- hopeless, helpless and pessimistic
- guilty or worthless
- a loss of interest or pleasure in activities that you once enjoyed
- that you want to harm yourself, which might include thoughts of suicide
- that you are unable to concentrate, remember things or make decisions.

You might also have physical symptoms of depression, which can include:

- unexplained aches or pains
- loss of, or increased, appetite
- sleeping more or less than usual
- slow movement or speech
- loss of sex drive.

If you have had depression in the past, you may be more likely to experience it after a diagnosis of lymphoma.

**Speak to your doctor, nurse or GP if you think you may be depressed.**



Write down who you feel comfortable talking to if you're feeling low.



- **NHS moodzone offers practical advice and interactive tools, videos and audio guides on stress, anxiety and depression. Visit [www.nhs.uk/conditions/stress-anxiety-depression](http://www.nhs.uk/conditions/stress-anxiety-depression)**
- **Mind has further information and support, including online forums, for people experiencing depression. Visit their website [www.mind.org.uk](http://www.mind.org.uk)**
- **You can also search for a depression support group on the Depression UK website [www.depressionuk.org](http://www.depressionuk.org)**
- **If in crisis, please contact the Samaritans on 116 123.**

## Coping with difficult feelings

Having lymphoma is challenging. There is no simple way of preparing for the range of emotions you might experience. You can, however, find ways to live well with lymphoma. Acknowledge how you feel and ask for the help you need. Counsellors, your medical team, your family and friends can all be a source of support. Just as you would use a crutch if you broke your leg, it is OK to need support if you are struggling emotionally.



### Tips for coping with difficult feelings

- Express your feelings. You could try:
  - speaking to a counsellor
  - talking to family and friends
  - writing down your thoughts and emotions.
- Make relaxation and enjoyment a priority. For example:
  - do things you enjoy
  - consider complementary therapies.
- Consider what you are able to control. You might find it helpful to:
  - learn more about lymphoma
  - make healthy lifestyle choices
  - set daily and weekly routines
  - choose what information to share and who to share it with.
- **Do what feels right for you.**



Write down things that help you cope with your feelings.



- Macmillan Cancer Support have a booklet called *Talking about your cancer*, which you may find helpful. Find it at [www.macmillan.org.uk](http://www.macmillan.org.uk)
- Our Information and Support team may be able to connect you with someone with a similar experience. Call 0808 808 5555 or visit [www.lymphoma-action.org.uk/Buddy](http://www.lymphoma-action.org.uk/Buddy)

# Stress

Living with lymphoma can be very stressful. Stress can have psychological effects, such as worry and anxiety, difficulty concentrating, irritability, sleeplessness and difficulty relaxing. It can also cause physical symptoms such as increased heart rate, headaches, muscle tension, dizziness, loss of appetite and nausea.



## Tips for managing stress

- Try to identify things that trigger your stress and get rid of any you can.
- Set aside time for your hobbies.
- Try relaxation techniques like breathing exercises, meditation or mindfulness.
- Try complementary therapies such as massage, acupuncture or aromatherapy.
- Look after yourself: eat well and exercise regularly.
- Be kind to yourself.



Use the figure above to write down your stressors and work out which ones you can do something about.



Moodjuice has information and tips on managing stress, sleep problems, anxiety and depression at [www.moodjuice.scot.nhs.uk](http://www.moodjuice.scot.nhs.uk)

## Relationships

Having lymphoma can put pressure on your relationships: some may become strained while others may become closer. As well as coping with your own feelings, you may feel pressure to deal with the emotions of family and friends.

People with lymphoma often say they feel other people don't understand them. You might have a sense that others expect you to get back to 'normal' soon after treatment. This can be frustrating and feel as if they have no idea what you have been through and continue to go through.

Many people with lymphoma say that others are careful not to upset them. We hear that people pretend not to see them or cross the road to avoid conversation. This is probably for fear of saying the wrong thing, but it can bring a great sense of loss and isolation. Some people find their friends react in a way they didn't anticipate: their closest friends may disappear and people they didn't expect to may make the most effort. Communication is important in maintaining relationships.



### Tips on talking to your partner

- Be honest about how you feel.
- Use 'I' statements to focus on you and your feelings rather than your partner's behaviour.
- Explain what you need and how your partner can support you.
- Don't be afraid to discuss sexual intimacy.

### Tips on talking to children

- You know your child best; trust your intuition.
- Be as specific and honest as possible.
- Use language your youngest child can understand.
- Talk to them about any changes to their day-to-day life.

### Tips on talking to friends and colleagues

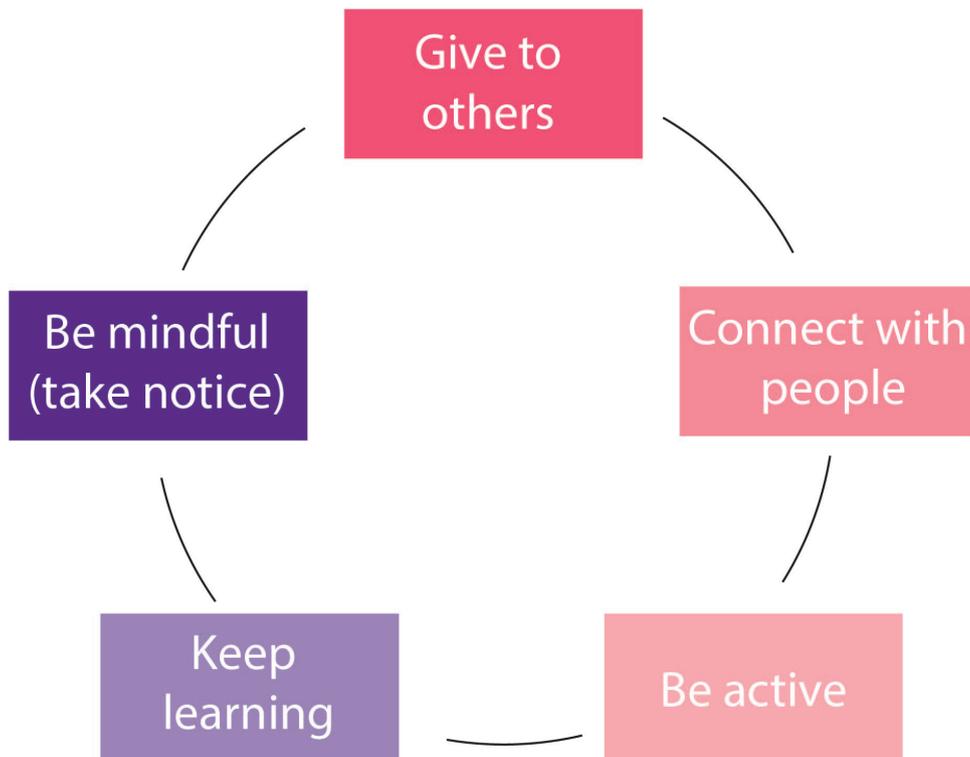
- Let people know how they can support you.
- Reassure them they don't need to feel pressured to say the 'right thing'.
- Consider asking someone to be a key contact to pass on information, or use social media to update a lot of people quickly.
- Instead of explaining lymphoma yourself, direct people to Lymphoma Action's website so they can learn more for themselves.

# Mental wellbeing

Mental wellbeing describes your mental health and your ability to cope with the stress of day-to-day life. It includes:

- confidence
- self-esteem
- contentment and enjoyment
- maintaining relationships
- engagement with the world around you
- productivity
- dealing with stress.

There are five steps we can all take to improve our mental wellbeing.



**Figure: The circle of wellbeing**



- For more information on the five steps to mental wellbeing, visit the NHS Choices website [www.nhs.uk](http://www.nhs.uk)
- Mind also has more information on mental wellbeing, including tips on how to improve it, at [www.mind.org.uk](http://www.mind.org.uk)

# Mindfulness

Mindfulness is a popular type of meditation. It encourages you to slow down and pay attention to the present – including the physical sensations you experience, your breathing and the world around you. Many people find that mindfulness helps them to manage stress and anxiety by allowing them to take control of thoughts before they become all-consuming.

You can be more mindful in your everyday life just by slowing down and noticing things around you, like sounds, smells and the feeling of a fabric or breeze against your skin.



## Tips on how to be more mindful

- Try practising mindfulness at the same time each day.
- Take time to notice sensations, smells, sounds, tastes and sights.
- Visualise your thoughts: if your mind is too busy to focus on mindfulness, try to picture your thoughts physically leaving your mind.
- Label thoughts and feelings: identify how you feel and name the feeling.
- Focus on the present: try not to relive the past or worry about events in the future that might not happen.



Make a note of things you'd like to try to improve your mental wellbeing.



- Visit Headspace at [www.headspace.com](http://www.headspace.com) to download a meditation app or sign-up for free online meditation tools.
- Download the free Smiling Mind mindfulness app or search for their YouTube channel to watch a series of mindfulness videos.
- Find out more about mindfulness on the Mental Health Foundation website [www.mentalhealth.org.uk](http://www.mentalhealth.org.uk), including a 10-minute mindfulness exercise.

# Useful organisations

**Cancer Research UK** provides comprehensive information on all types of cancer. Call **0808 800 4040** or visit **[www.cancerresearchuk.org](http://www.cancerresearchuk.org)**

**Citizens Advice** provides free, independent and confidential advice on benefits, housing, consumer and other problems. Call **03444 111 444** (England), **03444 77 20 20** (Wales) or visit **[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

**CLIC Sargent** provides specialist support for children and young people with cancer and their families. Call **0300 330 0803** or visit **[www.clicsargent.org.uk](http://www.clicsargent.org.uk)**

**Depression UK** is a self-help organisation for people with depression. Visit **[www.depressionuk.org](http://www.depressionuk.org)**

**Drinkaware** is an independent charity that helps people make better choices about drinking. Call **0300 123 1110** or visit **[www.drinkaware.co.uk](http://www.drinkaware.co.uk)**

**Macmillan Cancer Support** provides support and information for people with all types of cancer. Call **0808 808 00 00** or visit **[www.macmillan.org.uk](http://www.macmillan.org.uk)**

**Maggie's Centres** provide free support for people with cancer and their family and friends. Call **0300 123 1801** or visit **[www.maggiescentres.org](http://www.maggiescentres.org)**

**Mind** provides advice and support to anyone experiencing a mental health problem. Call **0300 123 3393** or visit **[www.mind.org.uk](http://www.mind.org.uk)**

**Moodjuice** offers information, advice and self-help resources to people experiencing troublesome thoughts, feelings and actions. Visit **[www.moodjuice.scot.nhs.uk](http://www.moodjuice.scot.nhs.uk)**

**NHS Choices** provides comprehensive health information to help you make the best choices about your health and lifestyle. Call **111** or visit **[www.nhs.uk](http://www.nhs.uk)**

**NHS Smokefree** provides motivation, information and support for smokers who want to quit. Call **0300 123 1044** or visit **[www.nhs.uk/smokefree](http://www.nhs.uk/smokefree)**

**Shine Cancer Support** offers support for adults in their 20s, 30s and 40s who have a cancer diagnosis. Visit **[www.shinecancersupport.org](http://www.shinecancersupport.org)**

**The Mental Health Foundation** is a UK charity that helps people understand, protect and sustain their mental health. Visit **[www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)**

**The UK Government information service** outlines what benefits you might be entitled to and how to claim them. The enquiry line is no longer available. Visit **[www.gov.uk](http://www.gov.uk)**

**Working with Cancer** is an organisation that helps people with cancer get back in to work or to find work. Visit **[www.workingwithcancer.co.uk](http://www.workingwithcancer.co.uk)**

# Acknowledgements

We would like to acknowledge the continued support of our Medical Advisory Panel, Lymphoma Nurse Forum and other expert advisers as well as our Reader Panel. In particular, we would like to thank the following expert for her assistance with this booklet:

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# References

These are some of the sources we used to prepare this information. The full list of sources is available on request. Please contact us by email at [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) or phone on 01296 619409 if you would like a copy.

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# About our information

Lymphoma is a complex type of cancer. Our award-winning information and publications can help you better understand your diagnosis, treatment and life beyond lymphoma.

Lymphoma Action's booklets give information on broad topic areas (for example they might cover all low-grade non-Hodgkin lymphomas and the types of treatment often given). They are professionally printed and bound and most are A5 size.

We offer our lymphoma information to you free of charge (UK only). If you live outside the UK, we recommend that you contact the lymphoma patient and carer organisation in your country as treatments and healthcare systems vary overseas. You can find a list of which organisations might be of help in your country on the Lymphoma Coalition website [www.lymphomacoalition.org](http://www.lymphomacoalition.org).

Lymphoma Action is committed to the provision of high quality information for people with lymphoma, their families and friends. We produce our information using nationally recognised guidelines, including the DISCERN tool for information about treatments, the NHS Toolkit for producing patient information and the Campaign for Plain English guidelines. Lymphoma Action is a certified member of The Information Standard independent quality assurance scheme, which is supported by the Department of Health.

Our publications are written by experienced medical writers, in close collaboration with medical advisers with expertise in the appropriate field. The most relevant references are listed in the publication. A full list of sources is available on request.



# Information and support

If you'd like to talk to someone about anything to do with lymphoma (including how you feel), get in touch.



Call our Information and Support team Monday to Friday on 0808 808 5555. You can also use Live Chat on our website



Come to one of our support groups. Find one near you at [www.lymphoma-action.org.uk/support-groups](http://www.lymphoma-action.org.uk/support-groups)



Join our online forum to chat with others who are affected by lymphoma



Get in touch with a buddy, someone affected by lymphoma



Visit [www.lymphoma-action.org.uk/TrialsLink](http://www.lymphoma-action.org.uk/TrialsLink) to find clinical trials that might be suitable for you



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## How you can help us

We continually strive to improve our resources for people affected by lymphoma and are interested in any feedback you might have about this booklet. Please visit our website at [www.lymphoma-action.org.uk/Book-Feedback](http://www.lymphoma-action.org.uk/Book-Feedback) or email us at [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) with any comments. You can also call our Information and Support team on 0808 808 5555.



**We produce other publications that give information about lymphoma and what to expect from treatment. Visit our website at [www.lymphoma-action.org.uk](http://www.lymphoma-action.org.uk) or call 0808 808 5555 for more information.**

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Check our website for the most up-to-date details of our services, including opening times.



**This booklet has been researched and written by Lymphoma Action, the only UK charity dedicated to those affected by lymphoma.**

**We would like to thank our incredible supporters whose generous donations enable us to offer all our essential support services free of charge. As an organisation we do not receive any government or NHS funding and so every penny received is truly valued. From everyone at Lymphoma Action and on behalf of those affected by lymphoma, thank you.**

**To get involved in fundraising for us or to make a donation towards our work please visit [www.lymphoma-action.org.uk/Donate](http://www.lymphoma-action.org.uk/Donate)**

This workbook complements the Live your Life workshop. It provides practical advice and information about living with and beyond lymphoma and has space for you to record information about your own lymphoma experience.

Lymphoma Action is a charity that has been providing information and support to people affected by lymphoma for over 30 years. We're here for you.



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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