



emhf men's health

WORKING WITH CANCER

a guide for men during & after diagnosis



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ABOUT THIS PROJECT

The European Men's Health Forum (EMHF) is the only European organisation dedicated to the improvement of men's health in all its aspects.

In 2016, the EMHF was awarded a grant by The Burdett Trust for Nursing as part of their themed grant programme on men's health to develop a nurse-led action plan to support men who are in paid employment and living with cancer through the development of self-care and self-management programmes.

Developed through consultation with a wide range of experts, health professionals, men with cancer and without, this manual is one of the outcomes of that project.

www.emhf.org

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Published November 2017 by the European Men's Health Forum supported by unrestricted grants from the Burdett Trust and Bristol-Myers Squibb (BMS).
Review Date: November 2020. References and feedback on emhf.org.

This edition is for the UK. The board, author and publisher have taken care to make sure that the information given in this booklet is correct at the time of publication. We advise you to find out as much as possible about any treatments prescribed for you and are not advising you to take any particular course of action. The board, author and publisher have no legal responsibility for any actions you may take after reading this publication.

The board, author and publisher do not intend this book to be used instead of advice from a medical practitioner, which you should always seek for any symptom or illness.

CANCER DOES NOT DEFINE US

Introduction

Does working with cancer work? The short answer is yes.

Last century most people with cancer died. Today most do not. Survival rates have doubled in the last 40 years and many are men of working age. (Men are more likely than women to be diagnosed with cancer under the age of 65.)

Of course, we're living longer which means more men are getting cancer than ever before. (Cancer Research UK reckon that by 2027 half of all men will get cancer in their lifetime.) And we're retiring later. It all adds up to this: working during and after cancer will become more common.

In the UK today there are already over 750,000 people of working age living with cancer. If you're reading this booklet, you're perhaps one of them. Everyone has a different experience of cancer – it's a physical challenge but it's also about how you feel and think about yourself, the world and your place in it. For all that, cancer doesn't have to change our attitude or approach to life: life is still what you make it.

Working can be important to men. It's not just about money and having a role or status, important though these are. Working can actually help recovery by providing something other than cancer to focus on and keeping things 'normal' (even if it's a 'new normal'). Work colleagues and your trade union can be a great source of support.

But getting work right after cancer is a personal thing. You may not be able to work or may want to do something else. There's no problem with this. You're no less a person if you can't work or don't want to.

What's right for you and what's right for others including your family, work colleagues and boss requires thought and well-informed discussion. That's what this booklet will help with. We hope you find it useful – there are links on page 11 if you want more information.

WORK

Work matters. Research suggests that about 2/3 of men with cancer think their job is as important to them after diagnosis as before.

Many of us want to work during or after cancer. How practical this is depends on what we were doing when we got the disease, what we can do now and who we work for.

Working through treatment

In many cases, it's not possible to work while having cancer treatment but if it is practical and you're physically and mentally able, you may want to. Be honest with yourself about why you want to do this. Maybe you need the money and feel you have no choice. You may be self-employed. But there may be other reasons. Thinking about these will help you understand how you feel about work and this greater self-awareness can make a big difference going forward.

Is it really practical? Make sure you know, as far as possible, what treatment you are having, where, when and for how long. Can anything be done to make it easier – perhaps treatment at a hospital nearer work? Talk to your cancer care team to ensure they think your plans will work for you and your treatment. Listen to their views. Make sure your employer knows exactly what is going on.

Not working through treatment

If you are off sick for more than seven days, ask your GP or cancer care team for a fit note (a sick note) to cover your illness. You need a fit note to get sick pay and to claim benefits.

If you're off for four weeks or more, you may want a Fit for Work referral. Talk to your employer and GP (and trade union and occupational health department if you have them). Along the way, keep your employer informed about what's going on. Your employer should be in touch with you too. All this can be a bit trickier, if you're self-employed – see page 7.

Returning to work

How do you feel? Desperate to get back to your job or hoping never to see

the office again? Both extremes are possible and everything in between – sometimes in the same day. Cancer is uncertain and our feelings about it change too.

You may feel differently a little later on so don't close doors you don't need to close. Equally, don't rush in. Think it through before making decisions. Consider all your options.

How does your family feel? They may want you to work but also feel guilty and not want you to go back too soon (especially if they feel your work is stressful). It's important that everyone tries to be honest about their feelings even ones they'd rather not have.

As well as your family, you'll want to speak to your care team, trade union and employer. When you're ready, develop a Return to Work plan:

- **when** you'll return - you'll want to be physically and mentally ready. How close you need to be to 100% depends on what you'll be doing and for how long but better to go back a week later than a week too soon.
- **how** you'll return - will there be phased return? Perhaps, a day or two a week at first. Discuss what suits you and your employer.
- **what** you'll do - will it be the same job? If not, what will be different? How will this affect pay, conditions, work/life balance, status etc?
- **'reasonable adjustments'** - do you need any changes to your duties, work tools or environment? ('Reasonable adjustment' is a legal term – see 'Your Legal Rights' opposite)
- **colleagues** - how will they be prepared for your return, especially if things aren't quite as they were before? Expect questions from some, awkward silence from others. Honesty is generally the best policy but how much you say is up to you – perhaps prepare some answers on cancer, treatment and recovery. The curiosity should die down after a few days.
- any specific plans for the **first day(s)**? Perhaps visualise the first few days back in your mind's eye. What situations may arise that you might want to plan for?

Your occupational health team, if you have one, can help with all the above.

Your boss's point of view

Talk to your boss about how best to keep in touch - text, phone, face-to-face? Perhaps a family member or work colleague can maintain contact for you – certainly in the early days when you've other things to think about. Perhaps they can come to any meetings with you.

Research suggests that most men with cancer are happy with the support they receive from their employer. But all of us can be wary of things we don't understand or jump to conclusions so, if you feel able, helping your employer understand your cancer and how it affects you can help you both. Your employer doesn't want to lose good staff (or end up in court).

Prepare for your communications with your boss. You could use this booklet as the basis for your conversation. Consider writing down what you want to say. What do you need? How can your boss help? Be very clear. Every cancer is different so even a boss who knows a bit about the disease will not know the specifics of yours and its treatment unless you explain. At the same time, make sure you know about the company's policies and your contract. Talk to your trade union if you have one.

Your legal rights

Hopefully, you'll be able to find an arrangement that suits you and your employer but, if not, people with cancer are protected by the law (although this varies across the four countries of the UK).

A survey by Macmillan found that about one in five people who returned to work after cancer faced some discrimination. This is illegal. So make sure you know your rights. You should not face any discrimination.

If you have cancer, you are protected under disability discrimination legislation (the Equality Act in England, Scotland and Wales; the Disability Discrimination Act in Northern Ireland). It applies if you are applying for a job or already have one.

Employers must make 'reasonable adjustments' to accommodate you. Examples include flexible working hours, time off for appointments, special equipment, revised duties, home working, moving your workstation (to be nearer a toilet, for example) etc. These adjustments may be temporary or permanent. You may also be entitled to help from the UK government's Access To Work scheme for aids and adaptations, travel, taxis and even a support worker. (Access To Work has been described as the best kept secret in occupational health so look it up.)

You're also protected at work if you're caring for someone with cancer.

Self employed or freelance

Being self-employed with cancer can be challenging. You may feel less supported: no HR department, no sick pay during treatment. But having control over your work may enable you to be flexible in a way that suits you.

In some cases, disability discrimination law applies if you're self-employed. Access To Work may be available too. You may need to look at doing things differently - doing less, changing working methods, getting help, varying your working hours. There is help available: government, business organisations and voluntary groups offer a variety of services to support small businesses. Many services are free. You may also be able to claim certain state benefits. And don't forget to check your insurance.

Not everybody who thinks they're self-employed really is. Some firms tell workers they're self-employed to deny them employment rights. If you're not sure if you're self-employed, check with Citizens' Advice. You may have more rights than you think. (You may also have more rights than you think on a zero hours contract - especially if you had one for a while.)

Working for a small employer

Don't assume small employers are less able or willing to help. No employer is exempt from equality legislation because of size and while smaller ones may have fewer resources (though not necessarily), they can be more flexible. It's particularly important to get advice, to talk to your boss and to ensure the firm knows all the help you and they are entitled to.

Doing something different

Cancer changes many things including our attitudes to work. You may feel unable to work; you may feel you want to do something else with your life or return to work later.

Are you interested in a different sort of work, or in working fewer hours, or in something less physical or stressful? You might find the US website Cancer and Careers (www.cancerandcareers.org) interesting. Remember, discrimination legislation also protects you when applying for a new job.

Whether you can choose not to work will depend on your own circumstances and those around you. Think about the level of income you need to meet your outgoings. Can you take your pension and/or early retirement? It's a big decision. You may want to talk to those close to you and get advice including probably independent financial advice.

Volunteering

Volunteering can be a way back to employment or a satisfying, useful activity in its own right. You can volunteer and claim benefits provided you still meet the conditions for the benefit and are only paid expenses.

Driving

In general, this shouldn't be a problem. Watch out for fatigue and the effects of treatment and medication. (You are responsible if you drive under the influence of drugs, even prescribed ones.) If your doctor diagnoses a side-effect called peripheral neuropathy (pain, sensitivity, numbness or weakness in the hands, feet or lower legs), you must tell the DVLA.

You may be eligible for a blue badge for disabled passengers/drivers.

MONEY

Money worries are not unusual in today's world. Add in cancer and it becomes especially important to keep on top of your family's cash flow.

Make two lists: money coming in and money going out. Then look at how to get more in the 'in' column and less in the 'out' column. Citizens Advice are used to helping with this. Or try your trade union or cancer organisation.

Income - look at all possible sources including work, benefits, sick pay, insurance policies, pensions and grants (from charities like Macmillan, for example).

There are more benefits than you might think. Cancer is a disability. You are entitled. If your cancer was caused by work you may be entitled to industrial injury payments. Make sure you understand your firm's sick pay scheme. (Are you entitled to more than statutory sick pay?)

Outgoings - you may be able to get help with housing costs (including rent or mortgage payments, council tax and home adaptations), health costs (including prescriptions - get an exemption card), travel costs (such as to hospital) and energy costs (talk to your provider). Also ask your mortgage provider how they can help. Parents may be able to get help with childcare, school clothing, meals and transport. People whose cancer cannot be cured may be entitled to additional help.

Look at all those regular payments. Any TV, phone or other subscriptions that you perhaps don't need?

Credit - if you have cancer you may find it more difficult to borrow money but if you can, be careful. It's easy for a short-term stop gap to become an expensive long-term burden. Consider independent advice before taking out any credit.

HEALTH

All you know about a healthy mind and body applies even more after cancer.

Exercise – the evidence for the benefits of exercise continues to grow. It boosts mind and body and improves sleep. Check with your health care team first but generally every little helps – even the shortest walk – and there are many exercise programmes out there specifically for people with cancer. Exercise is particularly important if you're at risk of treatment after-effects to your heart.

Food – you probably know what a healthy, balanced diet should look like: plenty of fruit and vegetables; not too much fat and red meat; no added sugar. This remains key after cancer but there is little evidence that special diets or 'superfoods' make extra difference. Food supplements are probably not needed unless you can't absorb nutrients or are at risk of osteoporosis.

If your immune system is less good, make sure everything is well cooked and avoid foods that might contain harmful bacteria (live yoghurts, raw eggs, unpasteurised cheeses etc).

Weight – keeping a healthy weight is important but, as you're probably aware, weight-loss can be a sign of cancer so, if you are shedding pounds for no obvious reason, tell your health care team. If you are trying to lose weight deliberately, take it slowly to maintain your strength and immunity.

For some personal advice, your doctor or nurse may be able to refer you to a nutritionist or dietician.

Drink – again, you probably know the basic advice: no more than 14 units of alcohol a week, no binges and a few non-drinking days a week. But keep an eye on your drinking. There is a link between alcohol and cancer and an even bigger link between alcohol and low mood.

Smoking – quit if you haven't already and avoid secondhand smoke.

Mental wellbeing – feeling a bit down and frustrated are normal with cancer treatment. Watch out for them turning into something more. Find ways to keep body and mind active, to relax and to talk about how you feel.

Of course, physical and mental health after cancer are big topics and not ones we can do justice to here. Your cancer care team are always there (even long after treatment has finished) and organisations like the Men's Health Forum have online information and booklets on all these topics.

'Am I disabled?'

As a person with cancer, you may not consider yourself to be disabled. However, Macmillan advise that if your employer or client asks if you are disabled, you should, for the purposes of the discrimination legislation, say 'yes'. This is because everyone with cancer is covered by these Acts and the term 'disabled' has a specific meaning under them. Some of the rights you will gain are outlined on page 7. Your employer may also have a disabled employees network you can join.

If you think you are being discriminated against because of your cancer, talk to your trade union, Citizens Advice or support line.

MORE INFO

THE LAW

NHS bit.ly/emhf-j

FIT NOTES

Cancer Research UK bit.ly/emhf-h

INFO FOR BOSSES

Cancer Research UK bit.ly/emhf-i

SELF-EMPLOYMENT

Mayo Clinic bit.ly/emhf-k

SMALL BUSINESSES

Macmillan bit.ly/emhf-l

ZERO HOURS CONTRACTS

Citizens' Advice bit.ly/emhf-m
[.gov.uk](https://www.gov.uk) bit.ly/emhf-n

TERMINAL ILLNESS

Marie Curie bit.ly/emhf-o

VOLUNTEERING

[.gov.uk](https://www.gov.uk) bit.ly/emhf-p

DRIVING

[.gov.uk](https://www.gov.uk) bit.ly/emhf-s

MONEY

Macmillan bit.ly/emhf-t
Citizens' Advice bit.ly/emhf-v
Money Advice Service bit.ly/emhf-u

EXERCISE

Cancer Research UK bit.ly/emhf-e

DOING LIFE DIFFERENTLY

Disability Rights UK bit.ly/emhf-y

SLEEP

Macmillan bit.ly/emhf-w

RELAXATION

Mind bit.ly/emhf-x

ORGANISATIONS/GROUPS

Cancer Research UK bit.ly/emhf-q

MEN'S HEALTH IN GENERAL

menshealthforum.org.uk

WORK IN GENERAL

worksmart.org.uk

WORK & CANCER IN GENERAL

macmillan.org.uk/work-and-cancer

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