

Physical activity the underrated 'wonder drug'



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We feature real-life stories throughout this report. Some photos are of models.

Unveiling physical activity as a hidden 'wonder drug' for people living with cancer

Every year in the UK hundreds of millions of pounds is spent on drugs to help prevent and treat cancer. Macmillan Cancer Support has discovered a 'wonder drug' with little cost. This report will outline hard evidence that simple physical activity can significantly help prevent cancer recurrence and also other long-term illnesses.



Until recently cancer was seen as something you were either cured of or which killed you. This has now changed and for many of the two million people now living with cancer it has become a long term condition – but they are not necessarily living well.

After treatment, learning to live with cancer is tough. Severe fatigue, depression, or reduced muscle strength can be immediate effects. People may not realise that heart problems and osteoporosis in later life are unfortunate consequences of cancer treatment.

So it is incredible to think that just by taking the simple step of getting involved in physical activity, cancer patients could possibly be helping themselves to overcome or even prevent these problems. What's more, in some cases it can significantly reduce the risk of dying from the disease. It seems so simple, but this idea is still news to many healthcare professionals and certainly to people living with cancer.

This report shows the hard evidence behind the theory that physical activity is a 'wonder drug'. We look at healthcare professionals who have already taken to the idea and are running some exciting projects to help people with cancer. Most importantly, we hear from the people whose lives have been transformed by taking part.

At Macmillan Cancer Support, we care passionately about making sure that people have the best possible chance to fight cancer. Let's do everything we can to help them look after their health and enjoy all the good things that life has to offer.

Ciarán Devane

Chief Executive

Macmillan Cancer Support

Cianan Devane



'After a year of extreme fatigue following treatment, I started regularly working out at the gym and doing yoga. I wanted to raise my fitness levels to help me tolerate my next chemotherapy in case I have to undergo it again. One positive side effect I had not counted on was a raising of my mood. My moments of post-cancer depression are now far less frequent or severe. Staying happy is another good reason for me getting out and getting fit.'

Richard, 37

Executive summary

There are two million cancer survivors in the UK¹ and Macmillan estimates that around 1.6 million are not physically active to recommended levels². Currently, the promotion of physical activity is not part of routine cancer care.

At Macmillan, we have increasing knowledge that physical exercise for people with a cancer diagnosis is vital. We wanted to quantify this knowledge to help us get the message across to doctors, nurses and commissioners.

To this end, Macmillan Cancer Support conducted a comprehensive evidence review of over 60 studies, commissioned a survey of 400 health professionals, and studied findings from pilot schemes which are commissioning and running physical activity services for cancer patients. We have used data from these three areas to produce this report, which finds:

Physical activity is appropriate

- The American College of Sports Medicine recommends exercise is safe during and after most types of cancer treatment and says survivors should avoid inactivity³.
- The Department of Health's guideline of 150 minutes of moderate intensity physical activity a week is appropriate for otherwise healthy cancer survivors, built up gradually⁴.

New evidence on physical activity

- Physical activity after treatment for cancer can reduce the impact of some debilitating side effects, such as swelling around the arm, anxiety, depression, fatigue, impaired mobility and weight changes⁵.
- Emerging evidence shows that achieving sufficient activity levels can reduce the risk of dying from breast, bowel and prostate cancer, and reduce the recurrence for breast and bowel⁶.

Lack of awareness of benefits

 Healthcare professionals are not sufficiently aware of this new evidence. One in 10 doctors and nurses still believe it's more important to encourage cancer patients to 'rest up' than undertake physical activity⁷. More than half know little or nothing about the benefits of activity in preventing or managing side/long term effects and only six per cent talk to all their patients with cancer about physical activity. Many believe it is not appropriate to do so⁸.

Cancer rehabilitation must include activity

- Physical activity should be part of standard NHS care for all cancers because of its impact on side effects.
- Comprehensive cancer rehabilitation services should include physiotherapy, exercise on referral, commissioned schemes in community leisure centres and signposting to walking groups and others.
- Every person with a cancer diagnosis should be offered a 'brief intervention' on physical activity to encourage them to gradually build up to 150 minutes of physical activity a week, with goals and written resources.
- Doctors need to be appropriately trained in behavioural change techniques such as motivational interviewing to helping patients, often demoralised through cancer, to get active.



The case for action

There are two million people living with and beyond cancer in the UK, and this is increasing by 3.2 per cent every year. If current trends continue, nearly four million people will be living with cancer by 2030°.

These people may be living with side effects and long-term effects of the disease and treatment, both physical and emotional, which make them feel they haven't 'beaten' cancer at all. Some may be visible during or very soon after treatment, or may take months and years to be seen. Many side and long-term effects can significantly affect quality of life.

According to a Macmillan survey, more than 70% say they're struggling with physical side effects between one year and 10 years after treatment¹⁰. These can include fatigue, weight gain, nerve damage, swelling around the arms, lymphoedema, blood clots, hot flushes and night sweats.

Reducing side effects and long-term effects

But there is increasingly strong evidence that physical activity can help prevent and manage these side effects caused by cancer or its treatment. The evidence review shows that physical exercise does not increase fatigue during treatment, and can in fact boost energy after treatment¹¹.

It can also reduce the impact of side effects such as lymphoedema, anxiety, depression and impaired mobility¹². Long term it is an effective way to help recover physical function, manage fatigue, improve quality of life and mental health, and control body weight¹³.

Reducing mortality and recurrence

There is a growing body of evidence that suggests physical activity can reduce cancer patients' chances of dying from the disease. Breast and prostate cancer patients can reduce their risk of dying from the disease by 30–40% if they do recommended levels of activity, compared to those doing less than one hour a week¹⁴.

Bowel cancer patients who do around six hours of moderate intensity physical activity a week could help reduce their risk of dying from the disease by around 50%, compared to those doing less than an hour¹⁵.

There is emerging evidence that it can also reduce the risk of the disease coming back for breast and bowel cancer¹⁶. This is significant as there are around 550,000 women who have been diagnosed with breast cancer and around 240,000 people who have been diagnosed with bowel cancer living in the UK today¹⁷.

Advanced cancer benefits

Physical activity can even help cancers patients receiving palliative care. A systematic review of six studies in palliative care settings suggests that important benefits can be gained from exercise in the last months of life, including improvements in physical function, symptoms and quality of life¹⁸.

Role of health professionals

The review shows cancer survivors are more likely to become more active if they are advised to by a health professional¹⁹, so their awareness and knowledge on the issue is crucial.

Macmillan's ICM online survey of 400 GPs, practice nurses, oncology nurses and oncologists – professionals who we know regularly come into contact with patients living with cancer – aimed to gauge their awareness and views²⁰.

'Get real, I have other things to talk about most of the time,' was one striking comment from an oncologist. This report finds that 'getting real' about physical activity will save lives. It should not be a substitute for drugs, but can play a significant role in conjunction with gold-standard medical care.

What's happening now?

Rest, not run

Historically, doctors would suggest that people with cancer should rest. Professor Jane Maher says: "Doctors and nurses would not have thought about the importance of keeping people moving after their treatment. I might have said 10 years ago after radiotherapy treatment, 'you will feel very tired but just go to sleep and go with it.'

"Now I would say it's really important to keep yourself moving after radiotherapy, aim to take a short walk three times a week – because it means your tiredness doesn't last as long."

Our survey shows that a worrying number of health professionals have not moved on. Around 1 in 10 doctors and nurses still believe it's more important to encourage cancer patients to 'rest up'; oncology nurses are more likely to believe this (16%).

Just over half of the doctors and nurses are not aware of the benefits in terms of preventing or managing effects, or reducing recurrence. 66% of the GPs surveyed say they knew little or nothing about activity preventing or managing side and long-term effects, and 73% say the same about reducing recurrence in breast and bowel cancers.

Not appropriate, nor a priority

Generally, over half of professionals surveyed say they speak to just a few or none of their patients about the importance of physical activity – rising to as high as 72% of GPs and 60% of oncologists.

Over eight in 10 of those who don't talk to all their patients about physical activity say the main personal barrier is feeling that with some patients it is not appropriate, predominantly because the patient is frail, but also because they have other long-term conditions, are old or unfit or simply because they don't bring it up themselves. Many may not know how to do so, particularly with older patients.

This is a paternalistic attitude and the issue should be explored with the patient. The evidence review clearly shows that frailty should not be considered a barrier. Some form of physical activity – perhaps toning, balancing and seat-based exercises – will be suitable for almost all patients, regardless of frailty.

Paternalism comes into play again, with some health professionals perhaps assuming that patients don't want to talk about physical activity. One clinical nurse specialist says: "Women are often very sensitive about their weight and will become defensive if subject is approached."

One oncologist explains that he didn't feel comfortable discussing activity, and 5% of oncologists say they do not feel it is their role to discuss it.

Almost four in 10 blame a lack of time and three in 10 blame a lack of signposting information to help them guide patients for not talking to patients about the possible benefits of physical activity.

Overall, physical activity seems to be a second order priority. With only six out of 10 professionals thinking it is 'crucial' to talk to cancer patients about physical activity, it comes well below talking to patients about the short-term and long-term effects of cancer or its treatment, despite the fact that physical activity could actually help manage or prevent many of these effects. This is particularly the case for GPs.

Whilst around eight in 10 professionals think physical activity should be a priority in any healthcare reform in general, only around four in 10 think it should be at the heart of cancer care.

No clear expectations

The American College of Sports Medicine recommended in 2010 that exercise is safe, both during and after most types of treatment for cancer, and said cancer survivors should avoid inactivity²¹. The British Association of Sport and Exercise Science mirrored that view a year later²².

This evidence shows that it is suitable to support otherwise healthy cancer survivors to gradually build up to the guidelines for the general population. Doctors and nurses need better information on this issue. Our survey shows that the majority of GPs and oncology nurses are unaware of the current DH guidelines – just 41% and 42% answered correctly.

The Department of Health's (DH) general guidance on activity is that adults take 150 minutes of moderate intensity exercise a week (with additional recommendations for strength and balance), but there are no specific recommendations for cancer patients²³.

Access and availability

The national picture of physical activity services, particularly those targeting long-term conditions, is varied. Some areas have exercise 'on referral' open to those with cancer, others don't. These are commissioned schemes, known as community referral programmes, where a GP or specialist doctor refers the patient to a 12-week course at a gym or similar exercise centre. But these are usually for patients with type 2 diabetes or high blood pressure. A cancer diagnosis does not necessarily entitle you to a referral.

Some specialists circumvent this. Jo Foster, Macmillan's Physical Activity Manager, says: "I know an oncologist who talks to his patients about activity. There is a local community exercise referral scheme, but cancer isn't on the list. High blood pressure, obesity and type 2 diabetes are, so he refers them in via that route."

One barrier to talking to patients is not having information to signpost patients to when it comes to providing advice on exercise. More than three out of 10 professionals and four out of 10 oncology nurses say they don't have any information on this. Eight out of 10 professionals say that having such information would be helpful in supporting them to encourage patients to become more physically active. Almost three in 10 also say that not having local places or courses they could signpost patients to is also a barrier. Six in 10 say that having such information would help them to encourage patients to become more active.

'It's like talking to a brick wall for some. If they haven't exercised most of their life so far, it's an uphill battle to get them to start when they've got cancer and are knackered by my treatment.'

Oncologist



What needs to change

Physical activity to be incorporated as a standard part of cancer care

The evidence review clearly shows the positive impact of physical activity on side effects. For this reason alone, it should be incorporated as part of standard NHS cancer care. This includes NICE clinical guidance and quality standards, the Department of Health tariff, the NHS Operating Framework and local authorities' Joint Strategic Needs Assessment.

NICE public health intervention guidance 2, recommends four ways of encouraging physical activity in inactive adults in primary care, one of which is a 'brief intervention'²⁴. This could involve a 20 minute discussion with the patient, with goals and written materials, encouraging them to do 30 minutes of appropriate exercise five times a week, followed up at regular intervals by the healthcare professional. GPs and primary care nurses should routinely consider these 'brief interventions' for cancer patients and survivors.

Awareness and education

Healthcare professionals play a vital role in educating patients. But they need both the evidence and materials to pass to patients. Macmillan can now provide these in the form of the concise review at macmillan.org.uk/movemore

More than eight out of 10 professionals said it would be helpful to have materials that they can pass to patients when talking to them about the benefits of physical activity. In this way they can seize what Professor Jane Maher calls the 'teachable moment' – the time during and after treatment when patients are receptive to new ideas and ways of living.

She says: "Once doctors know that it's important and see that lifestyle issues are particularly important for cancer survivors, then they are more likely to say 'I think you should take this seriously'."

Materials are also available at macmillan.org.uk/movemore

Training is also important, and Macmillan is working to create better training for health professionals. Clinicians need to learn how to support patients with behavioural change through motivational interviewing – a special technique that increases the individual's motivation to accept treatment by gently directing them, which is gaining credence in primary care. This maximises their success in helping patients often demoralised through the illness to get active.

Leisure services

Once engaged, patients need to be able to access appropriate local opportunities and services. It's important for the NHS to work with leisure centres and use facilities specifically for cancer patients, going further than offering general exercise referrals and also including leisure services in commissioning.

A number of leisure groups have health improvement managers who work sometimes in conjunction with clinical nurse specialists in local hospital trusts and authorities. We need more of them.

Economic benefits

A common theme in our survey was that healthcare professionals felt they did not have enough time to discuss physical activity with patients. One GP said: "Give me a 30 minute consultation, not 10 minutes."

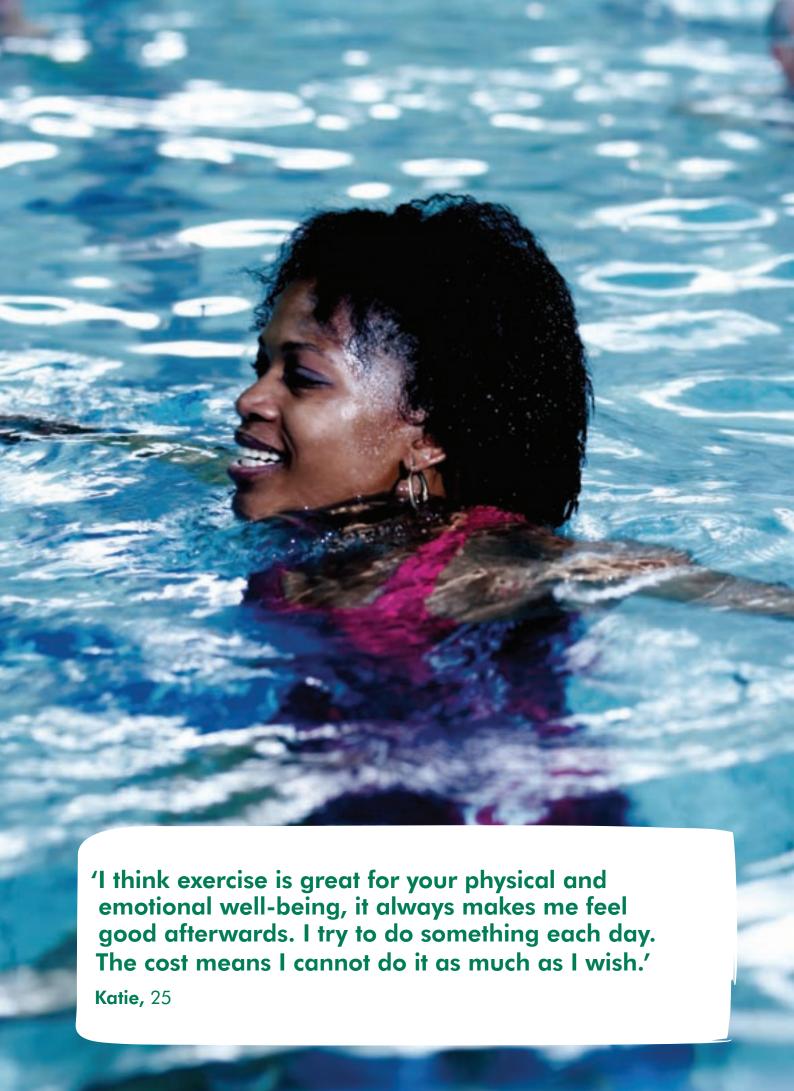
While budgets are being cut in the NHS, they may feel that longer consultations are a luxury the service can't afford. But longer consultations using motivational interviewing are likely to be more successful to encourage patients to take up physical activities.

More health economic analysis is needed in this area, but there are pockets of innovation across the UK where patients are benefiting from a variety of programmes, with potential cost savings to commissioners and the NHS.

For example, in Glasgow, the Active After Breast Cancer scheme offers all women attending a breast cancer clinic 24 free circuit-based exercise classes in local leisure centres. The classes are followed by lifestyle advice to help the women exercise independently.

A randomised controlled trial included in our evidence review shows that the women having adjuvant treatment for early breast cancer who took part in the scheme had fewer unscheduled NHS interventions – half as many in the exercise group spent at least one night in hospital. They also had fewer visits to their GP and reported significant improvements in physical functioning, quality of life and positive mood²⁵.





Innovation in services

There are a number of areas where physical activity services for people after cancer treatment are in place. These range from a fully commissioned all-round pilot service as a standard part of cancer care, to nurse-initiated physical activity programmes and support groups set up by individuals proactively seeking funding.

Macmillan wants to support best practice services for the NHS, and we have been working with pilots as part of the National Cancer Survivorship Initiative to integrate physical activity into patient care.

Bournemouth After Cancer Survivorship Programme (BACSUP) – a fully commissioned service

Two hundred cancer survivors were recruited for a 12-week physical activity programme run by a charity, BH Live, funded by Macmillan and the Department of Health. They were offered one-to-one motivational goal setting and activity guidance sessions, as well as activity sessions in the community, at a leisure centre, and even a dragon boat group called Pink Champagne.

BACSUP was so successful that a second year involving 250 patients has almost finished and a third year is planned. It is now a fully commissioned service included as standard cancer care in Bournemouth.

In the first year, blood pressure had dropped in 90% of the patients with previous high readings, 93 per cent had improved cardiovascular fitness, and 59% lost weight. As many as 94% said they felt less tired, 97% had improved well-being and all felt their self-image had been boosted.

Project leader Layne Hamerston, from BH Live, says: "Of all the conditions we work with, the impact I have seen around cancer has been most wide reaching. Some ladies come through who say they are fitter now than before cancer."

Active Luton – nurse initiated physical activity service

Louise Bolton, a Macmillan Primary Care Oncology Clinical Nurse Specialist, is working with Active Luton, which runs sports and leisure centres. It already works with the local NHS, running exercise referral schemes for people with diabetes and other conditions. A one-year pilot project will now include people during or after cancer treatment.

Louise says: "I strongly believe in the health benefits of exercise in well people, to combat stress and improve wellbeing. I want our cancer patients to benefit too. In Luton we have these amazing facilities and it might be about closing a pool so women with mastectomies feel comfortable about going swimming or offering a quick round of golf for men with prostate cancer. Exercise gives people a focus, so they don't just sit down and wait for the next day."



United Lincolnshire Hospitals' Health and Wellbeing Clinic – part-funded by Macmillan Cancer Support

United Lincolnshire Hospitals run one-stop-shop Health and Well-being clinics for urology patients who have just finished treatment. They are held outside clinical environments at times to suit people.

Each event features 'market stalls' where patients can speak to a range of clinicians including physiotherapists, oncologists, occupational therapists, clinical nurse specialists and mental health professionals, as well as volunteers from support and buddying groups.

There is a strong focus on providing advice and information on the best health care and lifestyle to minimise their risk of recurrence, and signposting patients to where they can get support, such as local walking and other exercise groups. They are given a voucher for one free entrance to a local leisure centre.

HOPE – Supported self-management

NHS Birmingham East and North and Heart of England Foundation Trusts ran a programme called HOPE as part of the National Cancer survivorship initiative which helped people learn to manage long-term symptoms.

This was done either through individualised coaching or group education courses that helped people learn how to manage effects of their cancer treatment more effectively, but can also enable them to understand their lifestyle challenges including need for increasing physical activity and weight control. The course helped motivate them to change their behaviour, with goal setting and regular follow up.

South West Fishing for Life – independent support group part-funded by a Macmillan grant

Somerset farmer Gillian Payne began offering monthly fly fishing sessions for women recovering from breast cancer and survivors at a local lake in 2008, and now the scheme has expanded to Cornwall and Devon. The sessions are led by a fly fishing coach who has had breast cancer herself.

Gillian says: "Fly fishing not only provides gentle relaxing exercise, but in this wonderful atmosphere it refreshes the soul as well. Our ultimate aim is to start groups throughout England."

Gillian benefitted from a Macmillan grant, which are available to any group of cancer patients wanting to do physical activity.



JO'S STORY

'Before cancer, I didn't like exercise. But when I was undergoing chemotherapy, I wanted to keep as well as I could. I have a Jack Russell, called Midget, and a Golden Labrador called Roxy and there were only two days that I didn't walk them. I had to keep Roxy on a lead so that she could pull me along — I didn't have a lot of energy.

When I first told the nurses that I was out with the dogs every day, they exclaimed and said I should be careful. I know they were just trying to protect me, but rather than being cooped up I was out and about. I really do think the exercise benefitted in keeping me free from any illness that could interrupt my chemo.

After the treatment, I began cycling and now do regular 12-mile cycles. I decided to do a five-day trek on the Great Wall of China in aid of Macmillan and have since gone on to do a six-day trek in Peru. I am currently training for a journey through the Himalayas. So far, I have raised over £14,000. Cancer has made me do so many different things that I would have never done before – I would probably have got to the age 70 still thinking 'I wish I had gone to the Great Wall of China'. It's given me a new zest for life – and I am hooked.'

Jo, 48, breast cancer survivor, from Somerset



Conclusion and solution – Cancer rehabilitation as standard

After a heart attack, it's accepted that that patients need cardiac rehabilitation, involving physiotherapy and appropriate physical activity.

Now it's clear that cancer rehabilitation involving physical activity is vital for survivors of the disease too, whether they have had surgery or not, to strengthen muscles and bones, improve fitness and weight management and aid well-being and mental health.

Getting active can help people overcome the side effects of cancer and its treatments, such as fatigue and weight gain. It can also lower their chances of getting heart disease and osteoporosis. Also, doing recommended levels of physical activity may reduce the chance of dying from the disease. It may also help reduce the risk of the cancer coming back.

More research needs to be done in this area, in particular to increase understanding about physical activity reducing mortality and recurrence in all cancers.

This report ends with a call to action: to cancer patients to get active, to doctors and nurses in primary and secondary care to help make that happen, and commissioners to fund these valuable services.

In particular, we recommend:

- Physical activity to be included within policy and to become a standard part of care for all cancers, because of the positive impact on side and long-term effects.
- 2 Comprehensive rehabilitation cancer services to include physiotherapy, exercise on referral, commissioned schemes in community leisure centres and signposting to walking and other exercise groups.
- Every person with a cancer diagnosis to be offered a 'brief intervention' of physical activity to encourage them to do the recommended levels of physical activity, appropriate for their age.
- 4 Training for doctors in behavioural change techniques, such as motivational interviewing, to help patients who are often demoralised through cancer to get active.





'I promised myself that when I had got through treatment, I would run a half marathon. My surgeon was not too keen and emphasised that I should not start running too soon. He has now agreed and I have started preparations for training. The benefits are many – psychological and physical. I wake up every morning looking forward to the new day and I am convinced that my general fitness helped me recover from surgery.'

David, 74

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Cancer is the toughest fight most of us will ever face. But you and your loved ones don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The fundraisers who make it all possible.

Together, we are Macmillan Cancer Support.

Questions about living with cancer? Call the Macmillan Support Line free on 0808 808 00 00 (Mon–Fri 9am–8pm) www.macmillan.org.uk

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