

AFTER CANCER TREATMENT:

A GUIDE FOR PROFESSIONALS



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CANCER SUPPORT**

This guide has been written and revised by the Macmillan Consequences of Cancer and its Treatment (CCaT) collaborative, led by members Mary Wells, Claire Taylor and Gillian Knowles, with additional editing by Alison Donaldson.

CCaT are a group of 12 research active nurses and allied health professionals brought together by Macmillan Cancer Support to influence healthcare policy, practice and research to improve the experience and outcomes of people affected by cancer and its treatment.

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More people are living with, or surviving cancer than ever before.

However, while their cancer may be cured, or at least controlled, many people experience long-lasting consequences related to the disease and its treatment (sometimes called late effects).

Health and social care professionals have an important role to play in supporting people to live healthily and have a better quality of life with and beyond cancer. They can do this by providing tailored education, building confidence, and helping people develop the skills they need to self-manage throughout their recovery.

How this guide works

This short guide is intended to accompany the Macmillan booklet *'What to do after cancer treatment ends: 10 top tips'*, a resource providing tips and advice for patients so that they know what to expect when they finish treatment and where they can go for further support.

This guide explains why each of the 10 patient tips are important and provides practical ideas and suggestions for how healthcare professionals can support patients in their recovery from cancer.

10 Top Tips for patients following cancer treatment

1. Discuss your needs and develop a Care Plan.
2. Ask about a Treatment Summary.
3. Find your main contact.
4. Be aware of any post-treatment symptoms.
5. Get support with day-to-day concerns.
6. Talk about how you feel.
7. Try to lead a healthier lifestyle.
8. Know what to look out for.
9. Be aware of your own health.
10. Share your experiences.

Taken from the Macmillan booklet ***What to do after cancer treatment ends: 10 Top Tips (MAC13615)***, written by the Macmillan Consequences of Cancer and its Treatment collaborative (CCaT).

The booklet is available to order free on **be.macmillan.org.uk**

Macmillan would like to see every patient receive a copy of these tips when they complete their cancer treatment.

Introducing the Recovery Package

The National Cancer Survivorship Initiative (NCSI) has developed and tested a number of key interventions, together called the 'Recovery Package'¹. These interventions could make an immediate difference to people affected by cancer, by helping them to prepare for the future and return to a lifestyle as near to normal as possible.



Each part of the Recovery Package is designed to work together to inform the overall care pathway.

- A **Holistic Needs Assessment (HNA)** should be carried out at or near diagnosis and at the end of treatment and again whenever health and social needs change, resulting in a written **Care Plan** outlining the actions to be taken to address identified needs.
- A **Treatment Summary** from the hospital team should inform the patient and GP about the care and treatment received, possible treatment toxicities and/or late effects, and the ongoing management plan and any required actions to support the patient.
- A **Cancer Care Review (CCR)** should be carried out by the patients GP practice three months following a diagnosis of cancer. This should include post-treatment support and information to enable self-management.
- Access to a **Health and Wellbeing education event**. Where all aspects of living with cancer as a long-term condition can be addressed to enable rehabilitation and self-management. This event should include advice about work and finance, physical activity and local services.

The elements above should be supported by improved information and support, including advice about, and access to, schemes that support people to keep physically active and make healthy lifestyle choices.

You can find further information on the Recovery Package, including, templates and evaluation reports and *Innovation to implementation, a how to guide* produced by NHS Improvement on the National Cancer Survivorship Initiative website at **[ncsi.org.uk](https://www.ncsi.org.uk)**

Although the NCSI was an initiative co-directed by the Department of Health in England, this guide uses the learning from the NCSI to benefit all patients across the UK and can be adapted to suit the local approaches being taken forward.

Tip no.1 – discuss your needs and develop a Care Plan

How you can discuss people's needs through assessment and care planning

Why is it important?

This is a great opportunity to engage people in decisions about their care and generate valuable information to develop a personalised Care Plan. This discussion can help people and their families adjust to the uncertainties associated with a cancer diagnosis and find 'a new normal' once treatment has finished.

Many people feel anxious at the end of treatment because support from their healthcare team is no longer so obvious. A Holistic Needs Assessment (HNA) carried out at point of diagnosis and again when treatment ends can help bring out these concerns and identify needs early.

There is evidence that a third of cancer survivors have five or more unmet needs following treatment². These may include:

- immediate or long-term physical problems
- difficulty returning to work, or discrimination when they do
- sexual and/or relationship problems
- fear of their cancer coming back
- feeling their social network has changed or can't meet their needs.

It's therefore crucial for you to identify each individual's likely needs for ongoing care and support.

As well as enabling you to assess your patient's needs, the conversation can ensure timely referral to rehabilitation or supportive care, prepare people for self-management and give them a sense of regaining control over their lives.

How can you help?

- To have a useful discussion, it helps to know the kind of issues a person may face after treatment. A number of HNA tools are useful here, including the Concerns Checklist, the Distress Thermometer, SPARC, PEPSI-COLA and others. Links to these tools and more can be found on **ncsi.org.uk** under Assessment and Care Planning.
- The tool you choose may depend on the needs of your patient group, the preferences of your team or the availability of electronic assessment tools. While HNA tools can form the basis of a productive and patient-centred conversation, the way they are used is as important as the tools themselves.
- You may already spend time with people at the end of treatment, but this conversation is designed to give each person a structured and comprehensive opportunity to share any concerns and discuss a future care plan. It's important to allow enough time. Our experience suggests it will take up to 45 minutes.
- The discussion can take place face-to-face, by telephone or even with the help of electronic communication such as email or e-HNA tools.
- Motivational interviewing and solution-focused techniques can be effective for this discussion. These interviewing skills help staff support and motivate people to seek their own solutions to problems, empowering and motivating them to make lifestyle changes and enable self management. There are several courses available on motivational interviewing, you can find a list of providers at **motivationalinterviewing.org**.

What is the Care Plan?

The Care Plan developed following the Holistic Needs Assessment sets priorities for care after treatment from the patient's perspective (an initial Care Plan should have been carried out at point of diagnosis and again following treatment). The plan explains the specific actions and approaches needed to address the person's needs. It includes a timeframe for each action, while recognising that some issues may not be quickly resolved.

It integrates information from different sources and may help coordinate care during the transition from acute to primary care. This is especially needed at transition points such as the end of treatment, when multiple teams may be involved.

The Care Plan is written with, and for, people who have completed an assessment and can be offered by any healthcare professional who has been involved in their care and will continue to offer them support.

How can you help?

- The aim of the Care Plan is to agree individual goals and preferences for further care so that the patient has a personalised self-management plan. For example, a patient may want to return to work as soon as possible after the treatment is over. In this case the plan enables you to document the reasons for returning to work plus the patient's plans, priorities and concerns related to this goal. The patient's plan might also include interventions to facilitate re-entry into the workforce, such as referring them to an employment support service, or providing advice on getting back to work and maintaining a healthy working life.



Useful resources

A Practical Guide for Holistic Needs Assessment

**[ncsi.org.uk/wp-content/uploads/
Holistic-Needs-Assessment-practical-guide.pdf](https://ncsi.org.uk/wp-content/uploads/Holistic-Needs-Assessment-practical-guide.pdf)**

Electronic Holistic Needs Assessment Pilot

**[ncsi.org.uk/what-we-are-doing/assessment-care-
planning/screening-and-assessment-tools/electronic-
holistic-needs-assessment-pilot/](https://ncsi.org.uk/what-we-are-doing/assessment-care-planning/screening-and-assessment-tools/electronic-holistic-needs-assessment-pilot/)**

UKONS e-learning package for Holistic Needs Assessment
and Care Planning **hnaforcancer.com**

Holistic Common Assessment of Supportive and Palliative
Care Needs for Adults with Cancer: Assessment Guidance.
London, Cancer Action Team (2007)

**[ncat.nhs.uk/sites/default/files/Guidance%20
holistic%20common%20assessment.pdf](https://ncat.nhs.uk/sites/default/files/Guidance%20holistic%20common%20assessment.pdf)**

Care plan builder

journeyforward.org/patients/patients

Department of Health. Living with and beyond cancer:
Taking actions to improve outcomes (2013)

ncsi.org.uk

Innovation to Implementation: Stratified pathways of care
for people living with or beyond cancer – a How to guide.

ncsi.org.uk

Tip no.2 – ask about a Treatment Summary

How you can complete a Treatment Summary

What is the Treatment Summary?

The Treatment Summary is compiled by specialist healthcare professionals within the multidisciplinary team with a copy sent to the GP and patient. It should include:

- the specific diagnosis: including pathology, stage and grade
- treatment: details and toxicities of all relevant cancer treatment including surgery, chemotherapy, radiation and targeted therapy
- identification of actual and potential long-term effects of treatment and suggested management
- surveillance plan for cancer recurrence: investigations and their frequencies
- recommendations for screening for secondary and new primary cancers
- risk reduction and health promotion strategies.

Why is it important?

The Treatment Summary provides key information to improve communication and continuity of care as people enter into the recovery phase after the end of their treatment.

The Treatment Summary can improve communication between the person who has had treatment, the specialist team and primary care providers. By providing all the information in one document it can ensure GPs and primary care teams have the details they need to promote and support recovery.

How can you help?

- Specific templates make completing the Treatment Summary much easier, especially if they're linked to a local computer system such as InfoFlex Cancer Information Management Services Ltd (CIMS) or Somerset Cancer Register. Before seeing the patient, pre-fill the entries where possible, such as treatment toxicities and common signs and symptoms of recurrence.
- Remember to provide a list of READ codes (a recognised coded thesaurus of clinical terms) so that the GP practices can record auditable data on their clinical computer systems, which is a mandatory requirement. Once all the information has been entered electronically, a letter to the GP can often be generated automatically. A copy of the letter should be made available to the patient so they know what treatment effects to look out for in the future.



Useful resources

Department of Health. Living with and beyond cancer:
Taking actions to improve outcomes (2013)

ncsi.org.uk

Treatment Summary guidance

ncsi.org.uk/what-we-are-doing/assessment-care-planning/treatment-summary/ and **[www.ncsi.org.uk/
wp-content/uploads/Treatment-Summary-User-Guide2.pdf](http://www.ncsi.org.uk/wp-content/uploads/Treatment-Summary-User-Guide2.pdf)**

Innovation to Implementation: Stratified pathways of care
for people living with or beyond cancer – a How to guide.

ncsi.org.uk

Tip no.3 – find a main contact

How you can provide a main contact

Why is it important?

During treatment people often report meeting a bewildering range of healthcare professionals. And once treatment ends, they find it difficult to know who to contact with questions and concerns.

Having a clear 'main contact' can reassure people and spare them the stress of navigating a complex care system without signposts. Coordinated care can lead to significant health benefits³.

After cancer treatment, most people continue to receive follow-up care with the specialist cancer team. The team should decide who is best placed to be the main contact. This should form part of the discussion arising from the HNA and must inform the Treatment Summary and Cancer Care Review.

Whatever happens, each person should know their main contact and how to reach them, including weekends and out-of-hours. This helps promote self-management.

How can you help?

- Give people clear information about who to contact, including out-of-hours details. Written information is best, like a patient information leaflet or a business card.
- This information may be most appropriate at the end of treatment but can be offered again (at the first follow-up appointment, for instance) and then reviewed on a regular basis, as needs change.
- During initial follow-up, the main contact is likely to be someone within the specialist centre or wherever the patient received their treatment. It could be someone from the cancer team, such as a clinical nurse specialist, who may already have acted as the main contact during treatment. This should form part of the discussion arising from the HNA and inform the Treatment Summary copied to the patient and GP.
- Beyond the formal follow-up period, the main contact is likely to be the GP or a member of the primary care team. It's important that the patient is clear when responsibility shifts from the specialist to the primary care team. This could be discussed and clarified with the GP at the patient's Cancer Care Review.
- Patients, GPs and hospital teams need to know whose responsibility it is to prescribe medication or investigate problems after treatment. The most appropriate main contact will vary from case to case and over time.
- The main contact needs to know what is expected of them, so it may be helpful to provide them with guidance about managing common problems and concerns.

Useful resources

NHS Innovation's Discharge Planning website
institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/discharge_planning.html

Innovation to Implementation: Stratified pathways of care for people living with or beyond cancer – a How to guide.
ncsi.org.uk

Care Transitions program (US)
caretransitions.org/definitions.asp

Carers UK Stages and Transitions in Caring
carersuk.org/professionals/resources/research-library/item/487-stages-and-transitions-in-caring

Salisbury NHS Foundation Trust Key Worker Operational Policy
icid.salisbury.nhs.uk/ClinicalManagement/CancerOncology/Pages/KeyWorkerOperationalPolicy.aspx



Tip no.4 – be aware of any post-treatment symptoms

How you can raise awareness of any post-treatment symptoms

Why is it important?

After treatment, each person can experience different side effects, these can be caused by cancer, the treatment or both.

It's important that the Treatment Summary includes information about the likely effects of treatment, both short-term and long-term. This information will also help inform the Cancer Care Review. If potential acute and late effects are known, the Cancer Care Review will be better tailored to each individual's needs.

Recognising symptoms sooner will ensure appropriate and timely access to care and may help to prevent longer-term problems. More information on the long term effects of cancer treatment is available in the 'Throwing Light on the consequences of cancer and its treatment' report.

How can you help?

- Give people information and advice at relevant points on how to recognise symptoms or problems. The end of treatment can be a good opportunity for exchanging information, but this should be judged on a case-by-case basis, as some people may not be ready to discuss long-term side effects at this time.

- Offer appropriate interventions to help people manage side effects. By informing them about how to take care of themselves, and the help that is available, you can boost their confidence and their ability to manage the condition. Ideally, specialist services will be scheduled into the pathway so that care can quickly be provided by the most appropriate member of the clinical team.
- Provide realistic timescales of what to expect and when. Many people are surprised how long it takes to recover after the end of cancer treatment.
- Both the Treatment Summary and Care Plan should be clear in the case notes, and be shared with the patient and the primary care team as appropriate.

Useful resources

Throwing Light on the consequences of cancer and its treatment report.

macmillan.org.uk/throwinglight

Oncolink Side Effects

oncolink.org/coping/coping.cfm?c=5

Cancer Health Centre at Boots

webmd.boots.com/living-well-with-cancer/default.htm

Macmillan Cancer Support: Symptoms and side effects

**[macmillan.org.uk/Cancerinformation/
Livingwithandaftercancer/Symptomssideeffects](http://macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Symptomssideeffects)**

Tip no.5 – get support with day-to-day concerns

How you can promote professional and peer support for day-to-day concerns

Why is it important?

The Recovery Package is designed to make sure that people recovering from or living with cancer are able to manage their health and day-to-day life with confidence.

People will have different needs, concerns, coping styles, adjustment strategies and perceptions of their recovery following treatment.

Some will turn to family and friends for their day-to-day support needs, such as money, employment, physical activity and diet. Others will need professional support.

While some people will feel able to ask for this help, many will try to manage without it. They may not want to bother busy professionals or they may assume others are in greater need. So it's worth making people feel that support for their day-to-day concerns is easily accessible after treatment ends.

To self-manage with confidence, people need to know about sources of help for issues like:

- ongoing symptoms and late effects
- knowing what symptoms are ‘normal’, and when to ask for help
- fear of the cancer coming back
- adjusting to everyday life
- adjusting to change
- getting back to work
- coping with financial and housing issues
- managing meals, housework and childcare
- trying to obtain insurance
- building confidence and self-esteem
- establishing or re-establishing relationships
- knowing how to build up activity levels and manage physical challenges.

How can you help?

- Encourage patients and their carers if appropriate to attend an education event such as a Health and Wellbeing Event. They offer information and peer support to enable rehabilitation and self-management around the issues listed above. These events form a key part of the Recovery Package by promoting health literacy and health behaviours, awareness of how to navigate the health care system and greater understanding of the support available.
- If there are no Health and Wellbeing Events locally, you may want to think about setting up your own. This could be a one-off event, a multidisciplinary clinic or a programme of patient education and support.
- Consider repeating or reinforcing information at different stages. It’s worth viewing this as an ongoing process that starts at diagnosis and continues throughout the whole treatment and recovery pathway. This requires partnership between primary, secondary and social care and the voluntary sectors.

Useful local organisations and resources you could recommend

- Local Macmillan Patient Information and Support Centre
- Macmillan Benefits Advice
- Maggie's Centre/local support groups
- Specialist allied health professionals such as dietitians and physiotherapists
- Working health and vocational rehabilitation services
- Lifestyle and physical activity programmes
- Local leisure centres, activity programmes and walking clubs.

Useful resources

Work and Cancer toolkit

be.macmillan.org.uk and search MAC13294

Self-help and support resources

**be.macmillan.org.uk and search
'Self help and support'**

Health and wellbeing events

**[ncsi.org.uk/what-we-are-doing/
health-and-wellbeing-clinics/](https://ncsi.org.uk/what-we-are-doing/health-and-wellbeing-clinics/)**

Macmillan financial support

be.macmillan.org.uk and search 'Financial support'



Tip no.6 – talk about how you feel

How you can support people to talk about their feelings

Why is it important?

For many people, talking about how they feel is a fundamental part of managing the emotional impact of cancer.

Emotional distress is common, but is often not properly recognised by healthcare professionals. A recent systematic review found that 20 to 30% of people who have survived cancer consistently reported ongoing psychological problems, including poorer quality of life⁴.

Being diagnosed with cancer is known to trigger a range of emotions, from shock and disbelief through to fear and anxiety. These emotions can be difficult to talk about.

People may find it particularly difficult to raise certain issues, such as sexual problems, with you. They need both permission and an opportunity to have a discussion about feelings and concerns. Often, they think that they should not take up your precious time because it's needed for people still in treatment.

After treatment, many people feel that they should now be able to deal with their own emotions and concerns, or that others expect them to be ready to move on.

Following cancer treatment, people are often unsure of what to expect next and can experience isolation when they are no longer in close contact with staff and other patients.

Evidence has shown that feelings of isolation and lack of support can have a real and negative impact on people living with cancer. This is why it's particularly important that the conversations conducted as part of the Holistic Needs Assessment and Cancer Care Review provide clear opportunities for emotional support, and that patients know where they can access further support as they need it.

On the plus side, we know that, for some people, talking about emotions and feelings can lower anxiety and distress, reduce feelings of isolation, and help them adjust to cancer.

Sharing emotions and concerns with loved ones can be painful, but often results in improved communication, better understanding and closer relationships. Some families and friends may become closer, while others become more distant.

The entire family is changed by the cancer experience, but they may not recognise these changes or the need for further support.

How can you help?

- Carry out a Holistic Needs Assessment at two key points in the care pathway (usually at or near diagnosis or at the end of treatment) and whenever health and social needs change. This will frame your opportunity to discuss concerns and how patients are feeling.
- Help people find opportunities to talk about their feelings both to you and their loved ones. Don't force the issue – bear in mind it can take time for some people to talk about their emotions.
- Encourage people to see their GPs and ask for a Cancer Care Review. Providing a detailed and timely Treatment Summary is likely to make the Cancer Care Review more useful.
- While basic communication skills like listening are crucial, you might need more advanced skills to help people manage their emotions. Training in emotional support, including cognitive behavioural techniques and solution-focused therapy, can be useful.
- Make sure you know how to recognise when someone requires specialist referral. Find out where you can access counselling, psychological or psychiatric help for people who experience severe psychological distress.
- Screening and assessment tools such as the Concerns Checklist or the Hospital Anxiety and Depression Scale are a useful way of determining whether emotional distress is likely to suggest clinical anxiety or depression requiring specialist input from clinical psychologists.

- Be aware of the local resources and expertise like counselling, psychology services, support groups, and befriender and buddy schemes. Macmillan Information and Support Centres, Maggie's Centres and other charity-led groups are an invaluable source of information and support for many people, and often provide access to specialist help.
- It's important for people to have different opportunities and alternative places to talk when they need support. There are a range of helplines and online forums provided by different cancer charities.
- Different people need support at different times. You can ask how they are feeling at regular intervals, with particular attention to possible trigger points such as diagnosis and end of treatment. You can also give them guidance on how to ask for help from others, or how to start a conversation on a sensitive topic with a loved one.
- The best person to provide emotional support depends on the individual patient, including where they received treatment, their family situation, where they live and how they prefer to seek help. Whoever they choose, communication between healthcare professionals, the patient and their family is critical. The main contact (see tip three) can provide a coordinating point.

Useful resources

Consider Macmillan booklets such as *“Talking to someone with cancer”*, *“Emotional effects”* or *“Relationships and communication”* – see macmillan.org.uk/Cancerinformation.aspx

Cancer Research UK: Cancer Chat
cancerchat.cancerresearchuk.org

Macmillan on-line community
community.macmillan.org.uk

Cancer Tales: communicating in cancer care e-learning resource
cancertales.org/elearning/home.html

Web-based CBT resources, eg Live life to the full, are evidence based and free to use
lltff.com

Screening and Assessment tools
ncsi.org.uk/what-we-are-doing/assessment-care-planning/screening-and-assessment-tools



Tip no.7 – try to lead a healthier lifestyle

How you can promote a healthier lifestyle

Why is it important?

Helping people lead a healthier life following cancer treatment is central to all parts of the Recovery Package.

People often review their health and reassess their lifestyle after cancer, particularly within the first year following diagnosis. In fact, because people are more open to messages about a healthy lifestyle at this time, a diagnosis of cancer has been said to provide 'a teachable moment'⁵.

Adopting a healthier lifestyle may help to reduce the common side effects of cancer treatment such as tiredness, depression and anxiety and also lower the risk of long-term consequences of cancer and its treatment, such as osteoporosis and cardiovascular disease.

However, behaviour change is complex and people need to be motivated to make changes and may face a number of barriers to overcome. Even people who are highly motivated may find it difficult to resume or start a healthier lifestyle after cancer. They may feel tired and unwell, have little spare time, lack confidence and be concerned about doing the wrong thing. They may also lack support from their carers, who think they should be resting up rather than being active.

How can you help?

- Determine the person's interest and level of motivation to take steps towards a healthier way of living. Bear in mind that healthy living messages have most impact when they are offered in small chunks and tailored to what the individual wants to know. Many people feel overwhelmed if you give them information on all recommended diet and lifestyle changes at once and if they seem resistant to health-promoting messages then it might be better to wait until another time. **It is important that the decision to make changes comes from the patient.**
- Motivational interviewing techniques can be useful in identifying how keen an individual is to change their behaviour and what barriers they perceive in making and sustaining such change. This form of communication uses a 'guiding' rather than 'telling' style of communication, helping to draw out possible solutions from the patient and build intrinsic motivation. In this kind of conversation you will need to listen and ask questions to try to understand the patient's perception of the issue. You should also resist the urge to impulsively jump in and give advice, but instead guide the patient towards coming up with their own solutions and plans.
- Introduce people to Health and Wellbeing Events. These are specifically aimed at enhancing healthy living, promoting physical activity and supporting people to make the transition from patient to person living with or beyond cancer.
- Where appropriate, involve family members and friends in discussions about lifestyle change, as there is evidence that people are more likely to change when more than one person in a social network takes part⁶.

- If the person is a smoker, ask how they feel about cutting down or giving up, and refer to the NHS smoking cessation service for follow-up advice and support.
- If you carry out a nutritional assessment, it might be appropriate to measure body mass, as well as waist and hip circumference. More detailed assessments of dietary intake and fitness levels can be undertaken by specialists.
- Check your local council's website and see if they run an exercise referral scheme, and whether it is appropriate for people living with and beyond cancer.
- Ensure information on local physical activity initiatives is readily available. You could promote opportunities by displaying posters and leaflets in clinic rooms.
- Recommend a local health walk. In England, Walking for Health is the largest network of health walk schemes, helping all kind of people to lead a more active lifestyle. Find local, free, led walks by visiting **walkingforhealth.org.uk**. Similar schemes operate in Wales (**lets-walk-cymru.org.uk**), Scotland (**pathsforall.org.uk**) and Northern Ireland (**walkni.com**).
- Bear in mind that the side effects of some cancer treatments may make it difficult for people to tolerate certain foods or to engage in moderate intensity exercise. The HNA will help to identify the individual's limitations and the Care Plan should be tailored to their specific capabilities.

Five key health messages to share with people after cancer treatment

1. EAT A HEALTHY DIET

The World Cancer Research Fund advises that people:

- limit consumption of energy-dense foods, particularly processed foods high in added sugar, low in fibre, or high in fat
- eat more of a variety of vegetables, fruits, whole grains, and pulses such as beans
- limit consumption of red meats, and avoid processed meats
- limit alcoholic drinks to two for men and one for women, if people choose to drink alcohol at all
- limit consumption of salty foods and foods processed with salt (labelled 'sodium' on the ingredients).
- avoid sugary drinks.

2. GET ACTIVE

Avoid inactivity during treatment and return to normal activity as soon as possible. Seek to build up to 150 minutes of moderate intensity activity each week, in bouts of at least 10 minutes⁷. A moderate level of activity noticeably increases your heart rate and breathing rate. You may sweat, but you are still able to carry on a conversation. You can talk, but you can't sing.

3. TAKE CONTROL OF YOUR WEIGHT

Aim to be as lean as possible, without being underweight. Excess weight can cause specific health problems, as well as affect how you feel about yourself.

4. STAY AWAY FROM TOBACCO

Smoking is associated with an increased likelihood of cancer returning, as well as to numerous other health problems, including heart disease, peripheral vascular disease and respiratory problems. Research shows that continued smoking is also linked to more severe symptoms during and after cancer treatment.

5. BE SAFE IN THE SUN

Take sensible precautions when out in the sun, such as keeping skin covered and wearing a sun hat.

Useful resources

Macmillan tools and resources on physical activity during and after cancer treatment

macmillan.org.uk/movemore

National Cancer Survivorship Initiative (2010). Lifestyle guidance for cancer survivors: executive summary

ncsi.org.uk/wp-content/uploads/Lifestyle-Review.pdf

World Cancer Research Fund (2011). Eating well and being active following cancer treatment

wcrf-uk.org/PDFs/EatingWellBeingActive.pdf

Food Standards Agency **eatwell.gov.uk**

Cancer Research UK, Healthy living section

cancerresearchuk.org

NHS Choices, Live well section **nhs.uk**

Living well with cancer health centre: Medical Reference related to living well with cancer

webmd.boots.com/living-well-with-cancer/medical-reference-index

Useful resources

Chief medical officer guidance on physical activity
**[dh.gov.uk/en/Publicationsandstatistics/Publications/
PublicationsPolicyAndGuidance/DH_127931](https://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_127931)**

Sport England **[sportengland.org](https://www.sportengland.org)**

Sport Scotland **[sportscotland.org.uk](https://www.sportscotland.org.uk)**

Sport Council for Wales **[sportwales.org.uk](https://www.sportwales.org.uk)**

Sport Northern Ireland **[sportni.net](https://www.sportni.net)**



Tip no.8 – know what to look out for

How you can prepare people to know what to look out for

Why is it important?

A recent Macmillan report estimated that at least 500,000 people in the UK living with and beyond cancer have one or more physical or psychosocial consequences of their cancer or its treatment. This includes chronic fatigue, sexual difficulties, mental health problems, pain, urinary and gastrointestinal problems, and lymphoedema. Certain treatments for cancer also increase the risk of other serious long-term conditions such as heart disease, osteoporosis or a second cancer. However a survey of people one to five years following diagnosis showed that many people were unaware of the long term physical and emotional aspects of living with and after cancer and would have welcomed more advice and information⁸.

Fear of cancer recurrence is also very common but people don't know what signs and symptoms they should be looking out for.

With this in mind, every part of the Recovery Package is designed to promote greater awareness of what to look out for to maximise confidence and minimise uncertainty for people living with and beyond cancer. Evidence suggests that broaching the possibility of cancer recurrence does not increase anxiety and may even reduce it – particularly for people who tend to cope by seeking information⁹.

How can you help?

- Let people know what changes in their health to look out for in the future. You could discuss what physical and psychological changes they might expect over time and when they should seek further help. Some people may need referral for psychological support.
- After their treatment is over, invite people to talk openly about their risk of recurrence and possible late effects of treatment.
- Establish whether they have any specific concerns about their cancer returning in the future and offer information on signs and symptoms that could indicate this.
- Ask if they have any questions about possible long-term or late effects associated with their cancer treatment.
- **It is essential** if they have symptoms or concerns, to direct them to their main contact (if it's not you) for a detailed assessment.
- Take advantage of the growing number of useful resources available on the long-term effects of treatment for certain cancers, and the ever-expanding evidence base for interventions.

Useful resources

Throwing Light on the consequences of cancer and its treatment report

macmillan.org.uk/throwinglight

Macmillan Cancer Support (2009). *It's no life: living with the long-term effects of cancer*

macmillan.org.uk/Documents/GetInvolved/Campaigns/Campaigns/itsnolife.pdf

Information on late-effects

cancer.net/survivorship/late-effects

Follow-up Care After Cancer Treatment –
National Cancer Institute

cancer.gov/cancertopics/factsheet/Therapy/followup

Macmillan late effects booklets and resources

macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Lifeaftercancer

Example of specific gastrointestinal guidance:

Andreyev J et al (2011). *Practice guidance on the management of acute and chronic gastrointestinal problems arising as a result of treatment for cancer*

Use **gut.bmj.com/content/61/2/179.full**



Tip no.9 – be aware of your own health

How you can support people to be aware of their own health

Why is it important?

The latest evidence shows that people surviving cancer would like to know how to look after themselves¹⁰.

This means creating an environment in which you support people to self-manage. All elements of the Recovery Package are designed to facilitate and encourage self-management by assessing individual needs, ensuring that patients and health professionals in primary care are given specific information about personalised treatment plans and what to expect, and providing opportunities such as a Cancer Care Review and Health and Wellbeing event.

By empowering and supporting people to achieve their personal health goals and manage any problems associated with their illness, you can increase their confidence and wellbeing. This in turn can give them greater independence, reducing demand on healthcare professionals.

Self-management may also result in earlier intervention, which can reduce anxiety and improve long-term health.

The warning signs of any episode of ill health can be subtle. People will only know when to be concerned and act swiftly if they pay attention to the signs within their body. Many people can feel uncertain about how to identify these signs and fear that they must react cautiously and seek medical advice or they might miss a serious change in their health. This can lead to unnecessary anxiety and occasionally an unsuitable medical investigation.

How can you help?

- Understand how people view their own health. This includes assessing their knowledge and attitudes to any planned follow-up, so that misconceptions and concerns can be addressed in advance.
- Encourage people to look out for signs that may be significant.
- Make sure people understand their schedule of care, as this may make it more likely they will attend important follow-up appointments.
- If someone appears overly preoccupied with their health since their cancer treatment, consider what psychological support you might be able to provide or refer them to in order to help them cope with their anxieties.
- Support healthy behaviours and lifestyle change (see tip number seven). This is a key focus of the Health and Wellbeing event.

Questions you could ask people at the end of treatment

- Now that your treatment has finished, can you tell me what you understand will happen next?
- Do you know who will provide your follow-up care?
- Do you know how often you will be seen for follow-up care?
- Are there any reasons why you would not be able to attend the tests or appointments scheduled?
- Do you know what routine blood tests and X-rays are available as part of your surveillance and how often?
- Do you know what to do if you suspect a problem?
- Do you have any questions about the proposed Care Plan?
- Would you like to change any aspect of this plan?

Useful resources

Motivational Interviewing guidance in Cancer survivorship
ncsi.org.uk/wp-content/uploads/MI-Project-Report.pdf

The Macmillan Organiser: a simple tool to help your patients manage their cancer treatment. It is designed to help them keep track of their treatment, make notes and find information and support they may need
be.macmillan.org.uk search 'Macmillan organiser'

NCSI Cancer Care Review
ncsi.org.uk/what-we-are-doing/assessment-careplanning/cancer-care-review/

Davies NJ and Batehup L (2010). Self-management support cancer survivors: guidance for developing interventions. An update of the evidence. Macmillan Cancer Support
healthpsychologyconsultancy.co.uk/documents/guidancefordevelopinginterventions_anupdateoftheevidence.pdf

Tip no.10 – share your experience

How you can encourage people to share their own experiences

Why is it important?

Many people going through treatment find it helpful to talk to others who have had direct experience of cancer.

And many people who have recovered from cancer treatment are happy to provide support and information to others.

Facilitating opportunities in your own service for people to meet, learn from each other and exchange suggestions can have real benefits for both patients and staff.

However, people do not always come forward to share experiences or to voice comments and concerns about the care they've received. Even if they do, they may be so grateful for their treatment and support that they emphasise all the positive aspects and avoid saying anything which might sound critical.

Offering people the opportunity to talk about their experiences of cancer and its treatment – both positive and negative – is important. Health and Wellbeing Events and support groups can provide the chance for people to share their experiences and also to support and educate others by acting as a volunteer.

How can you help?

- You could encourage people to reflect on what service improvements they would like to see. Having this feedback is crucial for a patient-centred service.
- Comment cards and brief questionnaires are a simple and relatively cheap way of getting people's ideas about services or planned service changes. As responses are anonymous, people are more likely to be honest. Another option is a brief 'How are we doing?' questionnaire alongside notice boards demonstrating how previous feedback has been acted upon.
- Raise awareness of research and provide information and opportunities for people to take part in suitable research studies.
- Communication tools such as Emotional Touch Points can help you understand patients and carers views and wishes. More generally, numerous resources and tools exist to encourage user involvement in care or to evaluate patient experiences. Some useful sites are listed at the end of this guide.

Useful resources

Emotional Touch Points

principlesintopractice.net/CaseStudiesandArticles/EmotionalTouchPoints/Emotional_Touch_Points.aspx

Building Strong Foundations – Involving People in the NHS, 2002

sehd.scot.nhs.uk/involvingpeople/bsftoolkit.htm

National Cancer Action Team User Involvement in Commissioning

ncat.nhs.uk/sites/default/files/work-docs/UserInvInCommissioning.pdf

Picker institute

pickereurope.org

(includes patient experience surveys and questions)

NHS Patient experience network

institute.nhs.uk/share_and_network/pen/welcome.html



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As a professional working with people affected by cancer you know that cancer is the toughest fight that most people will face and that no one should have to go through it alone.

We're here for you and the people you support. Please go to **macmillan.org.uk/professionals** to find out more about how we can support you in your role.

And please don't forget the Macmillan team are here to answer any questions the people you support might have on **0808 808 00 00** (Monday to Friday 9am–8pm).

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