THE RECOVERY PACKAGE

- Supporting self-management
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Introduction

The Recovery Package is a series of key interventions which, when delivered together, can greatly improve outcomes for people living with and beyond cancer. It is central to Macmillan’s objective of achieving its nine outcomes (see graphic below right).

Background to the Recovery Package

There are 2.5 million people living with cancer in the UK, and this is projected to increase to four million by 2030.¹ Research shows that one in three cancer survivors experience moderate to severe unmet needs at the end of treatment,¹ and for 60% of people, these needs have not yet been met.² These findings are supported by subsequent National Patient Reported Outcome Measures (PROMs)³, which have found that people with cancer experience persistent long-term problems. The PROMs survey also identified that if a person has one or more long-term conditions other than cancer, they are likely to have poorer quality of life scores. Even those with no other long-term conditions had poorer quality of life scores when compared to the general population.

Although more people are being diagnosed with cancer in the UK, more people are surviving a cancer diagnosis due to earlier detection and improved treatments. Cancer is moving from a disease where mortality was often the norm to one where more people can expect to live healthy and active lives for many years once their treatment is over. However, this also presents health and care services with the challenge of delivering sustainable healthcare to this group.

Transforming care

The increase in cancer prevalence and the evidence of unmet needs will require a transformation in the way that the NHS cares for people affected by cancer. This will mean moving away from the emphasis on acute and episodic care towards a holistic, personalised approach that is well coordinated and integrated. It also means moving away from using a single disease framework to a multiple disease framework.

The National Cancer Survivorship Initiative (NCSI) was set up in 2008 to address these challenges. Its aim is to: ‘ensure that those living with and beyond cancer get the care and support they need to lead as healthy and active a life as possible, for as long as possible.’⁴ The NCSI has developed and tested a number of key interventions, together called the Recovery Package. Its report Living with and beyond cancer: taking action to improve outcomes⁵ emphasises the importance of the Recovery Package in achieving better outcomes. It highlights that people will have greater well-being, and their demand for services will be lower, if they get the support that is relevant to their particular needs, and which promotes healthier lifestyles and independence.

Macmillan’s nine outcomes

By 2030, the 4 million people living with cancer in the UK will say:

• I was diagnosed early
• I understand, so I make good decisions
• I am treated with dignity and respect
• I can enjoy life
• I feel part of a community and I’m inspired to give something back
• I get the treatment and care which are best for me, cancer, and my life
• I know what I can do to help myself and who else can help me
• I want to die well
• Those around me are well supported

The Recovery Package also complements the introduction of stratified care pathways.⁶ This enables individualised follow-up care either through a supported self-management approach, with rapid access back into the specialist team should this be needed, or continued face-to-face follow up with health care professionals.
In 2009/10, the NCSI conducted an evaluation to identify the effectiveness of the implementation of the HNA and care planning process in 11 test sites. Test sites used a variety of assessment tools and covered four tumour sites – lung, myeloma, colorectal and head and neck. The evaluation took a mixed methods approach, which included a survey of patients considering their quality of life, confidence, physical activity and attitudes to information and assessment and care planning. Semi-structured interviews were carried out with doctors, nurses, project managers/coordinators and administrators across the test sites.

The evaluation identified a number of benefits to HNA and care planning. Professionals reported that the process allowed them to gain a greater understanding of their patients, which helped to identify and address specific problems and introduce different follow-up clinics. They also thought the process provided a number of organisational benefits, including improved staff satisfaction, rolling out learning to other parts of the organisation and making more appropriate use of time in appointments.

Professionals did report avoiding areas of assessments that were thought to be difficult topics. These often related to sexual issues for patients, which professionals often found uncomfortable to cover with patients during assessment and care planning.

The evaluation also found that overall assessment and care planning had provided a positive experience for patients. Patients reported that through the process they had been able to identify issues that were important to them and valued the opportunity to discuss specific practical problems, such as financial issues. Patients emerged from the process with a sense of being cared for and reported being better able to self-manage their condition. Patients also reported having improved self-confidence and more control over their situation.

Stratified care pathways

In 2011 and 2012 Ipsos Mori conducted quantitative and qualitative evaluations of the implementation of stratified pathways. The quantitative evaluation considered seven test communities, which included projects in tumor sites related to breast cancer, prostate cancer and colorectal cancer. The qualitative
work4 considered eight test sites.5  

It was found that stratified pathways empowered patients to self-manage their condition. 78% of patients responding to the survey stated that they had the information, advice and support that they needed to manage their condition. This finding was supported by the qualitative study, which found that the approach enabled patients to manage their conditions through the provision of information and support, and by health professionals working alongside patients to build their confidence.

The evaluation identified gaps in information around patients’ ability to identify the signs and symptoms of recurrence of cancer. Staff reported the need to proactively prompt questions and contact from patients. There were also gaps in information and advice on problems with erectile function. These were not addressed in 45% of cases where this was reported as an issue.

While this is an area that requires further information and advice, the findings are unsurprising given that the evaluation of assessment and care planning showed that staff are often uncomfortable discussing patients’ sexual concerns.

The qualitative study found that where stratified pathways do lead to self-management, this required staff to work in a different way, with a greater emphasis on ensuring patients felt reassured regarding their ability to self-manage. Staff thought assessment and care planning was useful in assessing a patient’s readiness for self-management.

‘Patients reported having improved self-confidence and more control over their situation.’

Of the patients that responded to the survey, 83% reported that they were more confident in managing their own care than before. However, patients also reported that the emotional impact of moving from treatment, where contact with professionals was frequent, to aftercare, where there was less planned contact with professionals, was difficult to manage.

The offer of supported self-managed pathways is in place at many centres across the UK. The Transforming Cancer Follow Up programme in Northern Ireland is implementing stratified pathways. Around 35% of people newly-diagnosed with breast cancer are being moved on to self-directed aftercare pathways including nurse led remote follow-up.6

Health and Wellbeing clinics
An evaluation of Health and Wellbeing Clinics was completed in May 2011.7 The events provide support for patients moving on after treatment, and assist in easing the emotional impact of this transition. They are supportive, group events that provide information, signposting and contact with peers.

The evaluation found that those that had attended the clinics had increased knowledge of the signs and symptoms of recurrence of cancer and how to re-enter the system if they needed to do so. This could work to fill the gap in information that was identified in the evaluation of stratified pathways. As with stratified pathways, these events were supportive in empowering patients to self-manage their condition, increasing their knowledge of local services and reducing anxiety regarding access to services. Patients also reported increased knowledge with regard to diet, physical activity and exercise and referrals to physiotherapy and dieticians.

The evaluation also found that patients experienced improvements in their quality of life, enabling them to better manage emotional distress and take part in social activities.

Events were most successful where a systematic referral process was provided through a multidisciplinary team and a wide range of services were promoted. Some events made use of volunteers and created opportunities for people who have experienced cancer to share their personal stories.

Summary and conclusion
Evaluation of the different elements of the Recovery Package has broadly been positive. However, more could be done to further improve the evidence base regarding the whole package.

Evaluations have consistently pointed out that implementing elements of the package requires a shift in culture away from dependence on professionals towards empowering patients.

People affected by cancer need to be provided with the confidence and reassurance necessary to self-manage and there is a need for clear routes back into the system. This requires a shift in thinking for both patients and staff in the health service.
Evidence base

Evidence for the Recovery Package and the need for change.

Holistic needs assessment
A key element of the Recovery Package is improving the holistic needs assessment (HNA) of people with cancer. Armes identified that of 1,425 patients, 30% reported more than five unmet needs after treatment. Another study of 741 men with prostate cancer found that patients had significant unmet needs following treatment. These findings were supported by the Patient Reported Outcome Measures of 4,992 people affected by cancer. Abrahamson reports that patient empowerment through the resolution of unmet needs can increase patient participation in care, and is especially important in terms of understanding the risks and benefits of treatment. Abrahamson identifies that there is evidence that even relatively simple interventions can reduce psychosocial and information needs.

Care planning
Recent publications by Hollingworth and Carlson have identified that screening for needs alone is not enough and there is a need for better triage to referral and better care plans. A concise evidence review of assessment and care planning was published by Macmillan in 2014.

Treatment Summaries
Information needs about the disease, its side effects and treatment emerge strongly for prostate cancer and other tumour sites. These relate to all aspects of the disease, from diagnosis, through to end-of-life care. Several studies have found that effective communication of information by health professionals was important to patients and that information-seeking by the patient was part of an active coping strategy. One of the studies identified that patients felt they could have been better prepared for what they might experience. Things like more timely and accurate information and resources to help them manage daily living, could have helped to meet their needs.

GPs need to have the same information as the patient to carry out an effective Cancer Care Review. This information is identified in a comprehensive Treatment Summary and the process for this is outlined in the user guide and in a previous issue of Sharing good practice.

Cancer Care Review
The Quality Outcomes Framework requires all GPs to carry out a Cancer Care Review within six months of receiving a confirmation of a patient receiving a cancer diagnosis. Campion-Smith identifies that this is the opportunity to explain the key role of the GP in giving support and information throughout the illness to the patient and their family. This complements the interventions of the hospital specialists. Macmillan Cancer Support has developed an electronic template for GPs to use, as in the past 54% of GPs had experienced challenges with completing this review. The Cancer Care Review was seen as different to other reviews for long-term conditions by GPs, and on evaluation said that they found the template easy to use.

Health and Wellbeing Clinics
Group therapy is a common method of delivering interventions for a number of conditions, including diabetes and smoking cessation. Group events provide the opportunity for social learning, generation of a shared emotional experience, and an opportunity to impart information and teach new skills. Literature and NCSI test site evidence suggests that group events are favoured by cancer survivors and that many find the experience valuable. They also find that meeting with their peers assists in the transition from patient to survivor and improved their psychological well-being. Group settings can also enhance self-efficacy and the ability to cope with personal health and well-being. "Innovations to Implementation: How to guide" outlines the way to implement Health and Wellbeing clinics/events. Health and Wellbeing clinics can ensure that people are well informed and physical activity can also play a role in preventing and improving some of the consequences of treatment.

Physical activity
Evidence suggests that being physically active during and after treatment for cancer can:
- improve physical and psychological well-being
- reduce the risk of consequences of treatment
- improve overall survival rates and reduce the risk of recurrence
- reduce the risk of co-morbidities (two or more medical conditions).

In 2006 National Institute for Health and Clinical Excellence reviewed the evidence for the promotion of physical activity and concluded that the approach was clinically effective both in the short and long term. As part of the Recovery Package the Lets Get Moving and Walking for Health programmes can be utilised by the NHS to enable health and care professionals to promote physical activity appropriately into patient care and across the care pathway.

Consequences of treatment
Many people with cancer experience short and long-term side effects from their cancer or treatment for cancer. There are a wide range of physical, emotional and social changes that can affect their quality of life and health and well-being after a diagnosis of cancer. Implementing the Recovery Package can help to identify the consequences of treatment.

Appropriate care planning can contribute to both prevention and appropriate care for those who have been affected.

Case Studies
Holistic needs assessment

Jane Wraight, Upper Gastrointestinal & Cancer of Unknown Primary Clinical Nurse Specialist (CNS), Dorset County Hospital (DCH)

It has always been a fundamental aim of the CNS role to identify and meet patients’ needs. In this sense nurses and allied health professionals have often done some form of HNA in the past, even when it has not been recognised as such or documented. More recently many CNs have been recognising the importance of undertaking formalHNAs, although anecdotal evidence suggests the subsequent production of a documented care plan has been less common.

There are benefits of doing a more structured HNA either on paper or electronically, as it helps to identify the patient’s real concerns that may not have been otherwise known. For example a person recently diagnosed with an Upper GI cancer who had many physical problems and who was also very anxious revealed that her anticipated biggest concerns were not...
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those expected by the CNS; they were an unexpected problem unrelated to her cancer that could still be addressed and improved. This reinforces that it is impossible to predict a person’s real concerns. It was felt important to recognise at an early stage that doing an HNA does not mean that all of a person’s concerns can be resolved. But at DCH there are already robust services in place, such as a benefits advice service, access to dieticians, counselling and specialised psychological support, which allow us to meet many needs.

Another benefit of any HNA is that it can be shared with any health professional involved in the patient’s pathway. In DCH, Upper GI cancer patients diagnosed with resectable oesophageal cancer have their surgery at the Royal Bournemouth Hospital. Patients who need pancreatic resections have these done in Southampton General Hospital, while radiotherapy is given in Poole Hospital. Care plans that are created after HNAs can be shared with colleagues across hospitals so they are fully aware of individuals’ concerns and plans to manage them. This gives much greater continuity of care and avoids unnecessary repetition. Continuity and co-operation across sites and teams can give patients a greater feeling of confidence and security. In DCH, allied health professionals are included in the HNA process. An oncology dietician plays a part in supporting patients to complete HNAs although the CNS retains the responsibility of discussing it with the patient and creating the subsequent care plan. DCH has also been a test site for stratified care pathways so we are working to link the Recovery Package into all of the services that we offer.

Patients have sometimes viewed self-assessment forms as another form to complete, similar to patient satisfaction questionnaires and some have not really engaged with it. But at DCH we also use the electronic HNA (eHNA), which is done using a tablet computer. The results of the assessment are then available to the CNS via a dedicated website called My Care Plan. The CNS can then develop a care plan specific to that person’s needs which can be given or sent to them. The tablets used have the tough packs on them making them less fragile. They are also able to be cleaned with alcohol wipes to avoid infection control problems.

In conclusion, this is probably one of the most exciting times of change and development within cancer services, with practical ideas and tools being adopted. The use of eHNA is a significant and powerful tool to help enable CNSs to do a better job in meeting people’s needs. And to quote one of the CNSs: ‘use of the eHNAs and individualised care plans feels like really good old-fashioned nursing.’

Health and Wellbeing Events
Kate Jenkins, Clinical Psychologist, Salisbury District Hospital

People undergoing cancer treatment experience a number of worries and concerns, not just about treatment or the future, but about financial pressures, family difficulties, body image and a host of other worries. People also consistently report feeling out of control, in that there is very little they feel they can do to help themselves. They feel totally reliant on the health system. This means that at the end of their treatment they can feel very deskilled and abandoned. An end of treatment group was set up by the psychologist at Salisbury District Hospital to support people finishing chemotherapy to move forwards. While this was very well received, recruitment was challenging and patients sometimes said they wished they had received some of the information sooner. At the same time, robust research evidence was emerging showing that physical activity was one of the few things that patients can actually do themselves to improve their outcome. We therefore decided to combine the original end of treatment group with physical activity under the supervision of specially trained gym staff. This was the start of the Health and Wellbeing Programme at Salisbury District Hospital, consisting of a psychosocial activity and support group, one to one gym sessions and a swimming pass.

The group is co-facilitated by a trained gym instructor and a clinical psychologist, with guest talks from dietetics, aromatherapy, financial advisers and other professionals.
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Each of the eight two-hour long sessions has a theme but also allows for more informal psychosocial support. Each session also includes an element of physical activity, ranging from a walk in the hospital grounds, to pilates-style stretching and even a zumba session. Patients are individually assessed to ascertain the appropriate level of activity for them and to take into account issues such as surgical restrictions.

Initial results from the group show a 70% decrease in symptoms of depression, a 35% decrease in anxiety and a 54% reduction in how much cancer related fatigue gets in the way of people’s daily lives. 66% of patients intend to continue to use the gym facility at the hospital. Many patients have commented on the good balance between a normal gym atmosphere, but with the reassurance of being in the hospital grounds. Subjectively, the group has been rated at an average of 9.8/10, with participants saying:

• ‘It’s a good mix of helpful information and encouragement to take part in gentle exercise but also the opportunity to talk, share experiences, fears and worries or just listen.’
• ‘The group was extremely flexible and sensitive to the needs of members.’
• ‘The course gave me confidence.’
• ‘Realistic, practical leaders who are skilled in making you feel at ease.’

As confidence and well-being improves we hypothesise that patients will feel more confident in their survivorship and may feel more able to move to models of self-directed follow up.

The programme also allows patients up to six one-to-one sessions with the gym instructor, if they would rather exercise alone. Patients can also access a protected swimming session, when the changing rooms are also only for the use of patients, allowing people the confidence to change and swim when they may have concerns about body image. This has been well-received, particularly by patients with significant scarring, stomas, or hair loss. Overall the programme is proving extremely successful and was recently shortlisted in the hospital Striving for Excellence Awards. The support from Macmillan has made this possible and we hope to make the case that programmes like this should be embedded in patient care and funded as part of their standard treatment.

Policy

England

Living with and beyond cancer: taking action to improve outcomes

This document details advice for commissioners and providers about the types of services that need to be available for cancer survivors. It starts to develop an evidence base, as a basis for action, for commissioners and providers, about what support cancer patients need, and how that support can be provided in the most cost effective way.


NHS outcomes framework (NHSOF)
The NHSOF is used to monitor the progress of the NHS Commissioning Board and to measure quality of cancer services at a national level. HNA will be essential for achieving the outcomes under Domain 2 (Enhancing quality of life for people with long-term conditions) and Domain 4 (Ensuring that people have a positive experience of care).

Visit tinyurl.com/7ffgd3

Clinical Commissioning Group outcomes indicator set (CCG OIS)
The CCG OIS is a key part of the NHS Commissioning Board’s approach to quality improvement. Its main aim is to support and enable CCGs and health and wellbeing partners to plan for health improvement by providing information for measuring and benchmarking outcomes of services commissioned by CCGs. It is also intended to provide clear, comparative information for patients and the public about the quality of health services commissioned by CCGs and the associated health outcomes.

Visit nice.org.uk/aboutnice/cof/cof.jsp

Improving outcomes: a strategy for cancer, 2011

This strategy puts patients at the heart of cancer services, notably by aiming to reduce the proportion of people who report unmet physical or psychological support needs following cancer treatment. Chapter 5 (Improving outcomes for cancer patients: quality of life and patient experience) acknowledges that patients’ needs include: psychological support, financial advice, support to self-manage, and information about treatment and care options.

Visit tinyurl.com/improvoutcomes

NICE quality standards

These standards are a set of statements designed to measure quality improvements within a certain area of care. HNA is included in some quality standards (end-of-life care for adults and lung cancer), but is absent in others (breast, ovarian and colorectal cancer), showing that HNA is not yet considered throughout the whole care pathway and for all conditions.

Visit nice.org.uk/aboutnice/qualitystandards/qualitystandards.jsp

Northern Ireland

Service framework for cancer prevention, treatment and care

The framework sets standards that span the whole patient pathway from prevention through to survivorship. Several standards include performance indicators on HNA and care planning to be achieved over three years to 2014. It was developed by the Northern Ireland Cancer Network on behalf of the Department for Health, Social Services and Public Safety.

Visit dhsspsni.gov.uk/sqsd_serviceFrameworks_cancer
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Transforming your care – A review of health and social care in Northern Ireland
This 2011 review sets out plans for the transformation of health and social care in Northern Ireland over the next five years. It promotes joined-up assessment and care planning. Visit tinyurl.com/transformyourcare

Scotland
NHS Scotland quality strategy
This strategy underpins the development of the NHS in Scotland. It has three ambitions related to quality (person-centred, safe, effective), all of which support assessment and care planning through a focus on self management and continuity of care. Quality outcomes two (People are able to live well at home or in the community) and four (Everyone has a positive experience of healthcare) are particularly relevant to HNA and care planning. Visit scotland.gov.uk/publications/2010/05/10102307/0

Transforming care after treatment
This programme is being delivered by the Scottish Government in partnership with Macmillan. It’s a new work stream of the Scottish Cancer Taskforce and assessment and care planning will be a major part of the programme. Visit qhub.scot.nhs.uk/programmes/cancer.aspx

Wales
Together for Health – cancer delivery plan
This plan sets out the Government expectations of NHS Wales in tackling cancer up to 2016. Local health boards are expected to assign a named key worker to assess and record the clinical and non-clinical needs of everyone diagnosed with cancer in a care plan. This includes regular assessment of the consequences of treatment, and other needs, such as access to financial, emotional and spiritual advice and support, to ensure a holistic, person-centred approach. Visit tinyurl.com/togetherforhealth

Resources

Macmillan resources for health and social care professionals

Assessment and care planning for people with cancer
This booklet for patients outlines the process of assessment and care planning, what to expect and what they can prepare for. be.macmillan.org.uk
Order code: MAC12957

Assessment and care planning folder
This pack contains two triplicate pads for the assessment and the care plan, sufficient for 100 assessments. This enables the user to give a copy to the patient, a copy to the GP or audit, and place a copy in the medical records. Replacement pads are also available (separate order code). be.macmillan.org.uk
Order code: MAC13689

Get active, feel good exercise DVD
In this exercise to music DVD, cancer and fitness expert Dr Anna Campbell, guides you through three exercise plans to complete at home. There is a booklet provided with the DVD, but you can also take a look at this booklet by selecting the download link below. be.macmillan.org.uk
Order code: Mac 14016

Health and Wellbeing clinics
This booklet provides a guide to Health and Wellbeing clinics for health professionals including case studies from pilot sites. be.macmillan.org.uk
Order code: MAC15174
Macmillan organiser
The Macmillan organiser is designed for the patient to help them keep track of treatment, make notes and find information and support they may need. It enables people to record useful information to help them self-manage and contains useful assessment tools such as the concerns checklist and mood and food diaries. be.macmillan.org.uk

Order code: Macmillan Organiser: MAC13281

Physical activity and cancer treatment
This booklet is written for people living with or after cancer who want to know more about the benefits of being physically active. It includes practical advice and useful organisations. be.macmillan.org.uk

Order code: MAC12515

Treatment summary – user guide and templates
A user guide and templates for the Treatment Summary, providing information to help you implement this change, the rationale for data fields, READ codes and the template to use. be.macmillan.org.uk

Order code: MAC13894

Work support route guide
English version
A signposting resource for health and social care professionals to guide people living with cancer who are in employment or on long-term sick leave, self-employed or out of work and want to discuss work options. be.macmillan.org.uk

Order code: MAC13538_ENG

Celtic nation versions also available.

What to do after cancer treatment ends: 10 top tips
This leaflet helps patients get the support they need to lead a healthy and active life as possible following cancer treatment. be.macmillan.org.uk

Order code: MAC13615

After cancer treatment: a guide for professionals
This short guide is intended to accompany the Macmillan booklet ‘What to do after cancer treatments ends: 10 top tips’. It explains why each of the 10 patient tips is important and provides practical ideas and suggestions for how healthcare professionals can support patients in their recovery from cancer. be.macmillan.org.uk

Order code: MAC14302

Videos
Please visit macmillan.org.uk/recoverypackage for more information and to see a video explaining the Recovery Package. From this page, using the menu on the left, you can view other videos about different elements within the Recovery Package:
- holistic needs assessment
- electronic holistic needs assessment
- health and wellbeing clinics

References pages i–iii
5 NHS Improvement. Stratified pathways of care... from concept to innovation. Executive Summary. 2012.
6 NHS Improvement. From Concept to Innovation. 2012.

References page iv–vi
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5 This phase involved 43 semi-structured interviews with patients, 16 interviews with staff in Trusts and 4 interviews with charity contacts.
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When you have cancer, you don’t just worry about what will happen to your body, you worry about what will happen to your life. Whether it’s concerns about who you can talk to, planning for the extra costs or what to do about work, at Macmillan we understand how a cancer diagnosis can affect everything.

No one should face cancer alone. So when you need someone to turn to, we’re here. Right from the moment you’re diagnosed, through your treatment and beyond, we’re a constant source of support, giving you the energy and inspiration to help you take back control of your life.

For support, information or if you just want to chat, call us free on **0808 808 00 00** (Monday to Friday, 9am–8pm) or visit [macmillan.org.uk](http://macmillan.org.uk)