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CARE AFTER CANCER

Research evidence supporting
Macmillan's promotion and
trials of a new approach
to cancer aftercare based
on four key principles

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December 2009

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Introduction

Macmillan hopes to gain ongoing support from the next Government for the National Cancer Survivorship Initiative [NCSI], a joint initiative between Macmillan and the Department of Health.

The initiative arose from the Cancer Reform Strategy and is testing new models of care for people with cancer whose treatment has ended. This is often a time when people with cancer feel abandoned and many experience ongoing problems due to their cancer or its treatment. However, their ongoing needs are not being met by the current follow-up system¹. It is estimated that a quarter of people treated for cancer (up to 500,000 people) are currently experiencing a consequence of cancer which has an adverse impact on the quality of their life². Macmillan is proposing that a new system of aftercare be introduced, based on four key principles:

- 1 Assessment at the end of treatment**
- 2 A care plan drawn up in partnership between the patient and healthcare professional**
- 3 Risk stratification of the patient to determine the likely level of ongoing support needed and to help inform the care plan**
- 4 Supported self-management of their condition**

This is a new system of aftercare that differs from the current follow-up system which focuses on surveillance. In addition Macmillan is proposing that people with cancer be provided with occupational rehabilitation (back-to-work support) to allow more cancer survivors to return to work.

There is currently a lack of clarity regarding the benefits of cancer follow-up care and therefore new models of follow-up, or aftercare, are being explored³. Key principles of future aftercare are the inclusion of comprehensive assessment at the end of treatment⁴ and the drawing up of survivorship care plans⁵.



Purpose and scope

The purpose of this document is to bring together evidence that supports these four key principles. The document draws on evidence collated by the Macmillan Survivorship Research Group in its activities and has not set out to scope new literature to identify evidence under the four principles. This evidence includes examples that aren't related to cancer, such as long-term conditions.

Assessment at the end of treatment

It is apparent that current assessment at the end of active treatment is inadequate and does not meet people's needs either for living with the consequences of cancer treatment or for health promotion.

Assessment can help people to identify what problems they are at risk of so that information and care plans can be drawn up to address these risks. There is evidence that adequate assessment can lead to improved health outcomes and information and support that is better targeted to meet people's needs. For example, there are no early symptoms of osteoporosis, a long-term consequence of cancer treatment, which can only be detected through appropriate assessment. Undetected osteoporosis can lead to severe debility and pain through vertebral, hip and other fractures. Accurate assessment can lead to effective interventions to decrease or reverse osteoporosis, preventing fractures, through the use of diet, exercise and drug treatment.

Ongoing problems at the end of treatment

People who have come to the end of active treatment for cancer report feeling abandoned by health professionals, yet there is evidence to suggest that they may have multiple, ongoing problems that are inadequately met⁶ and which affects their health to the same extent as people with other chronic illnesses⁷. People who have been treated for cancer are at risk of poor health and reduced quality of life due to ongoing problems with treatment related symptoms and other long term health problems that are a consequence of their cancer treatment. Ongoing cancer related symptoms include fatigue (20%-30% long-term cancer survivors⁸), psychological problems (20%-30%⁹) chemotherapy induced peripheral neuropathy (CIPN)¹⁰, urinary

incontinence¹¹, upper¹² or lower limb swelling¹³, ongoing post surgical pain (up to 72%^{14,15}) and generalised aches and pains¹⁶, while the long term consequences of treatment (late effects) include: damage to the lungs and heart, impaired thinking, infertility, second malignancies and osteoporosis^{17,18}. Cancer treatment may also have an impact on people's lives in a broader sense as their compromised health has effects on family life, sexual functioning, employment and finance. Long term ill health may result in increased utilisation of health resources and reduced capacity to work²⁰.

Some people require ongoing adjuvant treatment which may also have side effects, for example joint pains resulting from hormone therapies^{21,22}. These side effects may cause people to want to change or stop treatment altogether which may have a detrimental effect on cancer recurrence and mortality. Proper assessment and management of these side effects is likely to increase adherence to treatment. People do not always seek help for their problems¹² perhaps believing that they are a normal consequence of cancer treatment and that nothing can be done for them. However, for some problems, such as osteoporosis or lymphoedema (limb swelling), assessment and early intervention may hold the best promise for optimal management²³. In addition, physicians do not currently raise health promotion issues, for example, despite the risk of osteoporosis in women who have had cancer-induced menopause, one American study showed that only 56% of women had discussed bone health with their healthcare providers²⁴.

Health behaviours

Obesity may be a risk factor for recurrence and early mortality, for example in breast cancer²⁵. Smoking and alcohol consumption are also implicated in increasing the extent and severity of the long term effects from cancer treatment^{26,27}, while healthy lifestyle practices may prevent progressive or recurrent disease²⁸. Assessment of health behaviours such as smoking, alcohol consumption and diet, and hence implementation of appropriate interventions, can help reduce the risk of second cancers and recurrence and increase general health. Health promotion programmes have been shown to alter health

behaviours, for example taking up a healthy diet or smoking cessation^{27,29}. The timing of information delivery has been shown to be important³⁰ and, in cancer care, the end of treatment has been identified as a 'teachable moment'^{31,32}, where people are keen to learn more about how to manage their own health, yet require the skills and knowledge to do this²⁸. It is also clear that each patient has a different set of needs which therefore require individualised assessment and planning^{30,33,34}. Linking assessment to this critical moment when people are open to change is liable to result in an improved uptake of healthy behaviours.



A care plan drawn up in partnership between the patient and healthcare professional

There is currently no agreement as to what should be in a care plan but possibilities should be to address targeted needs of symptom management, health promotion, monitoring for recurrence and a return to normal activities.

Healthcare professionals and people affected by cancer need to work together to identify individual needs, particularly focusing on people most at risk of future problems requiring targeted input, and to draw up plans of supported self-management strategies. There is evidence from chronic conditions, such as asthma, that patient action plans and self-management education can lead to improvements in quality of life and a reduction in health service utilisation³⁵. The care plan is a key component of integrated care programmes, which have been used in chronic illnesses, such as diabetes and arthritis for many years and have positive outcomes such as improved functional health status and a reduction in hospitalisation, dependency and mortality³⁶.

Patient information

Many people, including healthcare professionals and cancer support charities, are involved in the provision of information, yet people with cancer still report lacking information³⁰ or direction from healthcare professionals as to how to access information and support³⁷. Information provision should provide a major part of the care plan drawn up at the end of treatment, as there is evidence that information provision has a positive effect on knowledge and recall, symptom management, patient satisfaction and

preferences and healthcare utilisation and that it is most effective when tailored to individual need³⁰.

Adopting healthy behaviours

As indicated above, the end of active cancer treatment has been identified as a 'teachable moment'^{31,32}, where people who have had cancer are open to suggestions about ways in which they might improve their health. Information about healthy eating, smoking cessation and exercise could be discussed at this time. There is much evidence that people who have had cancer alter their diet with the aim of improving their health or preventing cancer recurrence³⁸⁻⁴². Although there is little known about the effect of diet on cancer recurrence it is well known that an unhealthy diet is a factor in cancer development^{43,44} with specific foodstuffs being identified as either increasing or protecting against risk of cancer⁴⁵. Other protective mechanisms are keeping physically active and reducing weight⁴⁵. Obesity appears to be associated with increased mortality in breast cancer²⁵ and there is some evidence to suggest that a low fat diet can reduce the risk of breast cancer recurrence^{46,47}. Programmes of diet and exercise after cancer are effective in reducing obesity⁴⁸. Furthermore, dietary vitamin D and calcium, taken alongside exercise can help reduce bone loss⁴⁹.

Currently few cancer survivors take up exercise programmes, although there is evidence that a majority are interested in doing so⁵⁰. There is evidence that information and advice about physical exercise given by healthcare professionals during cancer follow-up can increase the uptake of activity which results in improved physical functioning and decreased fatigue⁵¹. Some will prefer tailored advice as to how they might exercise at home or at moderate intensity⁵⁰.

Once careful assessment of individual need has been made, a care plan can be drawn up which includes targets agreed by the patient and their healthcare provider. These targets might include plans for healthy behaviours, such as a plan for taking exercise, tailored to the needs of the individual, or how to implement changes towards a healthy diet. The care plan may include strategies for coping with ongoing symptoms, such as fatigue or pain and may give details of appropriate targeted sources of information and plans for future health surveillance.



Risk stratification of the patient to determine the likely level of ongoing support needed and to help inform the care plan

Determining levels of support

Effective care planning will also identify who is most at risk of poor recovery, high symptom burden and ill health with consequences for their quality of life. The majority of people who have had cancer are likely to manage their recovery from cancer well and do not need additional support⁵², however, there are substantial minorities who are at risk of poor recovery and will benefit from increased support. Targeting support to those most at need will not only provide the most appropriate care, but also be cost efficient. There is also a need to monitor those who are at high risk of cancer recurrence.

Those at higher risk of cancer recurrence

Evidence suggests that the current model of intensive follow-up and assessment of people with cancer does not result in increased detection of recurrence and is therefore expensive and unnecessary⁵³. Future models of follow-up, such as those based on nurse-led care, are likely to reduce hospital-based appointments and show adequate efficacy of follow-up with no increase in recurrence and reduced costs^{52,54}. However, there is a need to ensure that people who are at high risk of ill health, poor recovery from cancer or cancer recurrence are identified and appropriate levels of follow-up and support provided. Risk stratification will help determine which patients will benefit from more intensive follow-up. Different tumour types may have differing levels of risk, for example monitoring of recurrence for colorectal cancer is more useful than in breast

cancer⁵⁵. Definitive evidence about recurrence risk stratification and intensity of follow-up for breast cancer will be gained from a large national prospective study commencing in 2009⁵⁶ and in colorectal cancer similar information is expected to be reported in 2013³.

Those at risk of late effects

Those at risk of late effects from their treatment include children and young people and those treated with more aggressive treatments such as chemotherapy and/or radiotherapy. Treatments used in cancer, such as chemotherapy and radiotherapy, can have long term effects on health, particularly if given early in life. Late effects of chemotherapy include cognitive deficits^{57,58}, cardiac dysfunction, neuropathy, ovarian failure and skeletal problems following bone loss. Second malignancies, such as thyroid cancer, lymphoma and leukaemia may also occur⁵⁹. Targeted surveillance of those at high risk is likely to detect new problems early, and improve the chances of successful treatment.

Specific groups at risk of poorer long-term health

There is evidence that specific groups are at higher risk of increased symptom burden and less likely to take up sources of support, resulting in poorer overall long term health. People who are at risk of poor recovery due to symptom burden include the elderly who are more vulnerable due to co-morbidity, lower levels of social support and

are less able to access sources of support that are available, such as support groups⁶⁰. Ethnic minority groups are also at risk because they are less likely to take up sources of support⁶¹, partly due to the fact that the support sources are not always culturally and linguistically appropriate^{61,62}. For example, it has been suggested that some ethnic minority patients appear to experience worse pain than white patients⁶³. Targeting appropriate interventions towards those who have been identified as being at high risk has been shown to be effective in reducing disparities⁶³, improving symptom control and increasing quality of life. For example, Ashing-Giwa et al⁶² delivered a telephone counselling intervention to Latin-American women with cervical cancer and showed that an ethnically sensitive approach can achieve significant improvement in physical well-being and quality of life.

The disadvantages accrued by people from minority ethnic groups may not always be cultural and one study has shown that differences in quality of life outcomes are attributable to socioeconomic and life-burden factors and not to ethnicity⁶⁴. Another study of African-American cancer patients showed that most of the written information available to them was above their reading ability, however they still wanted all

available information⁶⁵, again indicating that disadvantage is due to educational level rather than ethnic minority status. People with lower levels of education are less likely to access sources that would support self-management activities after cancer, such as sources of information, support groups or self-management programmes⁶⁰ or to take up healthy activities, such as taking dietary supplements⁴². A risk stratification that identifies people disadvantaged by low literacy can enable targeting to ensure educational interventions at an appropriate level with resulting improvement in healthy behaviours³³.

Preparation for survivorship early in the cancer journey

While demographic, diagnostic and treatment details may provide most of the indication for risk stratification, there is also some indication that prior experience will have an impact on people's ability to self-manage their ongoing health needs. For example, one study shows that a measure of perceived preparedness for survivorship predicts who will benefit most from counselling and/or videoed support interventions⁶⁶, suggesting that interventions early in the disease trajectory to prepare people for survivorship may also be of benefit.



Supported self-management of their condition

Advantages of self-care and self-management

The effective management of chronic illness entails an active partnership between healthcare professionals and patient, combining professional expertise and lay experiential knowledge⁶⁷.

In this collaborative approach, the health professional's principal role is to encourage, facilitate and support the patient in their self-care activities³⁵. There is evidence that the majority of cancer survivors are well able to manage their own condition and transition to health⁵², although many want help with managing everyday problems associated with cancer and its treatment⁶⁸. A 2005 survey of the population in England indicates that there is interest in both practising self-management and leading healthy lifestyles⁶⁹. Where self-efficacy is increased in cancer (i.e. people's confidence in their ability to successfully self-care/self-manage) there are a number of improved healthcare outcomes, including improved quality of life, reduced symptom distress⁷⁰, reduced caregiver stress⁷¹, increased adherence to treatment, increased self-care behaviours and decreased physical and psychological symptoms⁷². Furthermore, without intervention, cancer patients become less confident in relation to self-care and adjustment and this is associated with poorer quality of life⁷³.

A finding from the Health Foundation report on self-management in chronic conditions was that although the objective is to give patients greater autonomy and control over their health, many of the studies point to the importance of regular contact between patients and those supporting them³⁵. People who have had cancer can be supported in their self-management activities by health professionals in a variety of ways, including education, psychological support,

coaching and motivational support and directing people to peer support opportunities. These activities can also be delivered in a number of ways, including computer based or telephone based approaches.

Self-management education

Self-management education is education that is aimed at assisting the patient to learn how to self-manage problems associated with their cancer or long term condition. In non cancer chronic conditions, self-management education has been associated with improvements in knowledge, coping behaviour, adherence, self-efficacy, symptom management and improved health status, with some evidence that this results in a reduction in health service utilisation and cost³⁵. Research has shown that programmes of education in cancer patients can increase perceived control⁷⁴, improve coping skills⁷⁵ and symptom management⁷⁶⁻⁷⁹. In cancer, programmes of education have been developed to assist patients to self-manage specific symptoms, such as cancer pain⁸⁰⁻⁸² or difficulties with weight and eating in advanced cancer⁸³. There is evidence that self-care activities can be taught to people with cancer who are then able to deal with conditions such as lymphoedema, by the use of self-massage, compression hosiery and skin care⁸⁴⁻⁸⁶ or hot flushes by behavioural activities⁸⁷ and relaxation exercises⁸⁸ or self-administered acupuncture⁸⁹.

Psychological interventions

Psychological interventions, such as stress management^{90,91} and psychological support programmes⁹² can increase knowledge⁹³, improve physical⁹⁴⁻⁹⁶ and psychological symptoms⁹⁷, improve quality of life^{97,98} and increase healthy behaviours, such as diet⁹⁹, exercise and smoking

cessation^{28,100,101}. One example would be where supportive psychological care and coaching can reduce fatigue after cancer treatments⁹⁴⁻⁹⁶. A number of psychosocial outcomes can be delivered through the use of support groups showing a variety of benefits for mental health after cancer, including an increased sense of personal control, increased coping, improved self-image, increased levels of knowledge, decreased isolation and decreased anxiety and depression¹⁰². Support groups may just be about shared experience and information or can deliver structured education or psychological interventions¹⁰². Both of these approaches are beneficial, although there is some indication that the structured approaches may be more beneficial for people newly diagnosed with cancer and that younger people were more likely to benefit from this approach¹⁰³. Support groups may also be 'virtual' (via the internet) and there is evidence that these groups can increase social support and decrease loneliness¹⁰⁴.

Self-management programmes

More structured approaches may take the form of specific programmes aimed at preparing people to cope with the transition to survivorship after cancer which have also been shown to be of benefit. These may be about recovering after cancer treatment or to help people adopt health promotion activities after cancer, for example in making long term changes to a healthy diet⁹⁹ and taking up exercise, which can have substantial and durable positive effects on cancer survivors' quality of life^{105,106}. Moderate intensity, individualised, prescriptive exercise can improve cardiopulmonary function after cancer treatment, resulting in reduction in fatigue and improvement in psychological well-being¹⁰⁷. Targeted exercise programmes for specific problems, such as arm swelling, can also be effective¹⁰⁸.

Technical innovations to support self-management

The use of a variety of technological innovations has enhanced the opportunities for supporting self-management from videos, CDs, computers and internet strategies to telephone support

and even self-monitoring devices. Videos have been effectively used to prepare women for the transition to survivorship at the end of active treatment⁶⁶, being more effective for some than counselling and also highly cost effective¹⁰⁹. Computer based support may be particularly effective for children and young people, where CD-ROMs have been shown to be more effective than written information¹¹⁰ and video games have been used to improve self-care in young cancer patients¹¹¹.

Cancer patients use the internet to access information and support^{112,113} and information accessed this way has been shown to increase self-efficacy and improve patient confidence in the clinical consultation¹⁰⁴. Interactive health communication applications in non cancer conditions (usually web-based packages for patients) have been shown to improve knowledge, social support, health behaviours and clinical outcomes¹¹⁴, and reduce depression and anxiety¹¹⁵. Furthermore, there is evidence that computer based cognitive behavioural therapy (CBT) may be as effective as therapist led CBT in reducing anxiety and depression¹¹⁶. Costs of a personalised information system are no more costly than general computer information and may be considerably less than full patient access to written information¹¹⁵. Further benefits of computer based information have been shown to be increased levels of social support and greater benefits for disadvantaged groups, such as those with rare cancers and those who are geographically isolated^{115,117}.

Telephone interventions can be used in a variety of ways, and have been used to empower patients in their own care, in a variety of chronic conditions, including diabetes, hypertension, cardiac failure and AIDS³⁵, showing benefits in general chronic disease management with some reduction in social isolation, improved self-efficacy, quality of life, patient empowerment and psychological outcomes. In cancer care telephone support has been used during active cancer treatment to monitor for chemotherapy symptoms⁷⁵, for pain assessment and self-management¹¹⁸, to replace traditional medical



follow-up at the end of active treatment¹¹⁹ and ongoing support to maintain health behaviour change⁹⁹. Telephone care is often in conjunction with other modes of care delivery^{120,121}. Telephone care by nurses has been shown to have high satisfaction and acceptability by patients^{122,123}. Some groups have used the telephone to provide peer support¹²⁴ and it has been suggested that telephone support may be better for people who want to remain anonymous, those with rare cancers and those who are geographically isolated¹¹⁷. Telephone support can also be a useful component of successful, long-term health behaviour change when used for coaching and motivational input⁹⁹.

Self-monitoring of health

Self-monitoring of health status and treatment regimens have been effectively used in chronic conditions such as diabetes and high blood pressure showing cost saving due to decreased utilisation of health services, and appearing to be as effective in health outcomes³⁵. These devices are beginning to be introduced into cancer care, although there is little evidence at this time to support their use. Self-care diaries have been used during chemotherapy to record side effects and self-care actions⁶⁵ and, more recently, cancer patients have used online, real time report of symptoms when undergoing chemotherapy¹²⁵.

Conclusion

It is clear that healthcare after cancer treatment can be altered in a way which is beneficial to the person living with cancer and which may decrease dependence on current expensive hospital follow-up services. Proper assessment of need, targeting of resources at those most at risk, and providing support for self-management is likely to improve people's recovery after cancer and enhance their quality of life as well as increasing healthy behaviours which may have enduring health benefits.



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