

Macmillan Cancer Support's offer to support the development of -
Cancer information and support and benefits advice services for people affected by cancer

1) Introduction

Those who work in health and social care are well aware of the serious long term health care issue we face as a nation. Lengthening of life expectancy means an increasing population of elderly citizens, often with multiple health conditions. Changes in life-style are also increasing the incidence of some particular health conditions.

Discerning patients expect care which is the best available and which meets their personal needs. They also expect to be active participants in decisions about their care. For people to be able to participate in their care and make informed choices they must be provided with the necessary information. All of these challenges need to be met within inevitable financial constraints.

Macmillan Cancer Support successfully campaigned for the information and support needs of people affected by cancer to be recognised, as well as the specific issues relating to the need for people to be given expert advice on financial issues, benefits and returning to work.

This document outlines the ways in which Macmillan can offer support to organisations regarding the provision of supported information delivery to people affected by cancer. Macmillan works with statutory, (NHS bodies and local authority organisations) voluntary sector organisations and private sector partners to support high quality information, support and financial support services.

2) Our position on information and support and benefits advice provision

‘Face-to-face’ communication with appropriate professionals is essential so that those affected by cancer can understand their condition and situation, reveal their concerns and preferences, and engage in decisions about their care.

People affected by cancer should be offered high-quality information throughout their cancer journey, which is tailored to their individual needs. Some patients will need additional support to understand and act on the information they receive whether this be about their cancer diagnosis, treatment or any related social and financial issues they may have.

Information delivery is key at each step in the care pathway, reinforcing and supporting face-to-face communication with a health professional. It should be available in primary and secondary care and from other outlets such as dedicated information and support centres, libraries and through partner organisations (e.g. Citizen’s advice bureaux (CAB) or Local Authority in relation to benefits advice).

Information needs to be evidence based, balanced, regularly updated and composed in plain language. It needs to be culturally sensitive and available in a variety of formats. It should include personalised details, be tailored for local services and focus on a patient’s needs at that given point in time.

‘The purpose of communication and information is to inform and empower patients so they can play an active role in decisions about their care and treatment if they so wish.’
(Macmillan Cancer Support)

The provision of information is a skilled activity for which health and social care professionals need to have adequate training. Supporting a cancer patient through

information involves personal contact with a skilled individual who is able to guide them through any questions or needs they may have regarding information on cancer and its effects, their financial issues or the benefits available to support them. The skilled individual might be a health or social care professional, a specialist cancer benefits advisor, an information specialist or a trained volunteer.

Key to delivering this agenda is the development of information prescriptions in England and similar initiatives in the rest of the UK. This involves the provision of professional, quality information tailored to the specific needs of the individual person. The information prescriptions are provided in a way that takes account of the need for human interaction to make its delivery effective.

Macmillan is working with relevant Governments to deliver information prescriptions and with local providers of health and social care to ensure that the outcome of 'every person with cancer getting an information prescription at key points in their cancer journey' is achieved.

3) What is Macmillan currently doing to support the Information provision agenda?

Macmillan's strong vision of supporting this agenda is based on the development of six fundamental offers:

- Digital information and support services via our [Macmillan website](#) for people affected by cancer to use and health professionals to direct people to. The website includes an [interactive online benefits guide](#) that will help people affected by cancer find out more about benefit entitlement
- Macmillan National [Direct Cancer Information and Support Service](#) via phone including a telephone based benefits advice service (on 0808 808 0000) and on-line. All health professionals can direct people to these services, or the public can access them directly
- World-class information leaflets with validated content from www.be.macmillan.org.uk
- Training for professionals in information and support delivery and benefits awareness as well as training for people affected by cancer to support self management via www.learnzone.macmillan.org.uk
- Supporting the development of local cancer information centres, benefits advice services and additional support in hard to reach or rural communities from Mobile Macmillan Cancer Information Centres
- Supporting local providers of health and social care to plan and deliver the role out of information prescriptions.

If you require any further information on any of these service offerings please contact your local Macmillan Service Development team who can provide you with further details.

4) Why develop information and / or financial support services in your area in partnership with Macmillan?

Quality

Macmillan UK wide provision – if you incorporate Macmillan’s direct services, leaflets, website and helpline into your information pathways you can be sure the information is verified, up to date and quality assured. The website is accessible 24/7. During the day and into the evening, if someone cannot access a professional they can access other Macmillan direct services. In addition the Macmillan service can support people with other language needs. This service is not designed to be a substitute for good local information or specialist financial advice provision but it will support and complement your local activity.



Local provision – Macmillan has years of experience in developing information and support centres and benefits advice services in acute and community settings. We have validated models of service delivery that demonstrate quality provision. As you develop your local services, the quality assurance a Macmillan partnership can bring will add value to your local initiatives. The development of your professionals locally can also be supported by Macmillan to ensure they have the skills they need to develop and deliver good quality information and/or specialist financial support.

The key to quality provision of information of any type is the quality of the content and delivery in a way that meets the person’s needs. The most important aspect of this is the provision and availability of face to face support. For example someone who can go through an individual’s information needs and concerns helping them to fully understand the information and make the right decisions for them and their family. For those who have financial concerns someone who can offer support with advocacy, case work and representation is invaluable.

Innovation

Macmillan provision – Macmillan’s information provision is cutting edge and a leader in its field. The interactive website provides one of the best sources of cancer specific information and benefits application support in the UK. The merger with Cancerbackup in 2008 has provided Macmillan with the opportunity to provide information in a range of formats on a scale never seen before in the UK. If your organisation approaches Macmillan, there is scope for innovative local solutions that incorporate Macmillan’s direct services.

Most of these benefits are independent of your income or savings.

The benefits covered here are:

- * Statutory Sick Pay
- * Disability Living Allowance: Care Component
- * Disability Living Allowance: Mobility Component
- * Attendance Allowance
- * Carer’s Allowance

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Local provision – Macmillan Service Development teams have the skills and experience to support you to adapt our tried and tested models of service provision for your local needs. Macmillan is always keen to support innovative developments and has a long history of innovation in working with health and social care. We are an effective partner, offering advice and in some cases ‘invest to save’ funding to develop innovative solutions.



Productivity

Macmillan provision – Macmillan can provide your organisation with a cost neutral service to complement your local face to face services. By working with Macmillan Service teams and incorporating Macmillan’s direct services (the Macmillan Support Line and website) in your local provision you can ensure that more people can be supported with no extra cost to you.

Our advice and support can supplement your local provision, and ensure that you do not need to set up additional helplines or websites for cancer information, support and financial help locally. The provision of a comprehensive information and support system for people affected by cancer can help streamline their access to services and help prevent inappropriate visits to professionals or health care facilities.

Local provision Information Centres

The development of local information and support provision will provide patients and families with the information they want and need when they want and need it – not just at their clinic appointments. This reduces the number of questions that people need to ask during busy clinics, home visits or at GP practices, but also helps people to ask the right questions during the time they do have with health professionals. A good information centre can make the interactions with health professionals more effective and support the high volume of people who have only limited access to professionals but have significant information and emotional support needs.



Specialist Benefits advice - Evidence has shown that people who have the support of local specialist benefits advice services claim more of the benefits that they are entitled to, supporting them to stay at home and reducing the level of stress associated with the financial issues which are frequently experienced by people affected by cancer.

Cancer Information and Support services and Cancer Benefits Advice services help people to understand their individual needs and access the services they need quickly and appropriately. This means that they get to the right person, place or treatment in the first instance preventing delays and potentially the development of additional problems.

Prevention

Macmillan Provision – Although Macmillan's focus is not on the provision of information to prevent cancer (as there are other organisations much better placed to support this work) Macmillan is keen to prevent unnecessary pain, suffering and distress. Improving quality of life and avoiding the potential costs of inappropriate treatment are both issues that Macmillan information services support.

It is well recognised that good, informed decisions are the most effective way to provide cost effective treatment and the key to this is well informed patients and families. The use of the on line benefits package can support people who are happy to complete the complex documentation involved in claiming benefits themselves, ensuring they are better equipped to understand the questions being asked. This often prevents people inappropriately being turned down and additional appeals.

Local provision – Although the focus of local information or financial services is not necessarily the prevention of illness, they do provide information and advice which can help people to make choices which will reduce the risk of ill health or complications. In the case of the specialist benefit advice services they can also prevent appeals or being rejected for benefits that they are entitled to.



In summary the provision of our information and financial support services can prevent or reduce:

- emotional distress or anxiety with all of the associated implications
- inappropriate access to health professionals or other services
- unproductive discussions with health professionals when ill informed patients and families don't know what to ask or expect
- poorer quality of life for patients who are not accessing appropriate support due to lack of awareness
- incorrect information being given to patients that may cause unnecessary stress and inappropriate clinical or treatment decisions
- delays in receiving support or benefits and having to recomplete applications for support if turned down due to lack of knowledge of the system

For further information on any of the Macmillan offers described in this paper, please contact your local Macmillan Service Development team about what can be achieved. An overview on each of these offers can be provided to support further discussion about what may be possible to develop locally.

5) Supporting Evidence

Macmillan has developed a briefing paper that discusses in more depth the evidence available on the need for and delivery of Supported Information Provision and Supported Financial Information Provision.

These can be assessed along with all our other evidence based papers via the following section within Macmillan's web site

www.Macmillan.org.uk/servicesimpact