

Celebrating 20 years of Macmillan cancer information and support services

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Acknowledgements

This report is dedicated to the many people who have committed their time and used their expertise to develop Macmillan cancer information and support services since 1993.

Your efforts have benefited people affected by cancer in England, Scotland, Wales and Northern Ireland, and without your passion, enthusiasm and energy we wouldn't be where we are today. Since 1993, the number of services has grown from one to 171 – to have achieved such spread in just 20 years is especially impressive.

Thanks to Macmillan working in partnership with health and social care organisations, people affected by cancer have access to a wide range of services, such as information, emotional support and benefits advice.

Thank you to all the dedicated information and support staff, both paid and voluntary. Roles vary throughout the UK, as do the types of services on offer. Services are provided in hospitals, GP surgeries, libraries and elsewhere in the local community.

Thank you to all the cancer information centre managers, clinical professionals and information specialists, information and support volunteers, complementary therapists and fundraisers.

And a special thank you to all those who make that very first supportive cup of tea.

'I just wanted to say thanks so much for all your help, the services and support Macmillan provided were instrumental in my treatment and recovery, and I can't praise you enough.'

User of the Richard Hambro Macmillan Cancer Information Centre, London

With special thanks to the following for your recollections, research and overall contributions to this report: Jenny Freeman, Simon Henderson, Ruth Carlyle, Jane Maher, Kim Diprose, Harjinder Sahota, Peter Kent, members of the Improvement team, and the Lynda Jackson Macmillan Centre team. Thank you also to Rachel Bowden, Alison Donaldson and Mig Muller for taking the time to read and comment on the draft report.

Executive summary

Every day, 889 people are diagnosed with cancer in the UK. Today there are two million people living with cancer nationwide and we expect this to double by 2030.

Research tells us how valuable positive experiences in the healthcare system can be. And improving that experience by providing local cancer information and support can make a real difference to a person's quality of life. It can help to improve their physical and mental health, their financial situation and their ability to manage living with cancer. There is evidence linking improved quality of life to faster recovery, earlier discharge from hospital and a reduction in the use of statutory services.

Access to appropriate information to inform decision making is now regarded as a health service in its own right, rather than an add-on service to other treatment and care.

For 20 years, Macmillan has invested in developing and improving the information and support available to people affected by cancer, with over 350,000 directly benefiting last year alone. This report takes the opportunity to reflect on how things first started, what we learned on the way and – more importantly – the next steps on the journey.

Though much has changed since Macmillan made their first direct investment in an information and support service in 1993, what people affected by cancer want remains the same today. A 2003 review of services showed how valuable Macmillan information and support services are in enhancing the experience of those who use them. It also suggested that services should:

- be tailored to the needs of each individual, and offer guided access to information and support
- be complementary to the work of the clinical team
- take a holistic view of users' needs by considering the range of support and care they may require
- provide suitable services on-site or signpost users to the places where they can get help if needed.

Only by working in partnership with Macmillan cancer information and support services can we achieve our vision. That is, that all people affected by cancer, and their family and carers, will have the information and support they need throughout their cancer journey, so that they can make the best decisions for them about their treatment and their lives.

THOM'S STORY

Being diagnosed with colon cancer at 27 came as quite a shock to Thom. 'It's beyond reality really – especially when you're a perfectly fit 27-year-old guy.'

Emergency surgery followed by 12 courses of chemotherapy left Thom feeling 'like a complete zombie'. But Macmillan's Mustard Tree Centre at Plymouth Hospital was there to support him. 'It was unbelievable – it's a little bit of heaven, the perfect environment.'

There he found support from the Macmillan team including Denise, a benefits adviser, who helped him successfully claim the benefits he was entitled to and also apply for a Macmillan Grant. Thom's family was not local and, as he had been self–employed, his savings and money quickly ran out. This meant the financial help Denise helped provide was a vital lifeline. 'I genuinely wouldn't know where to start if it wasn't for Denise.'

The therapy proved successful and he decided he wanted to give back immediately. He organised a cricket match which raised £20,000 and now wants to scale even greater heights, literally, by climbing Everest and raising £1 million. 'I've no doubt in my mind I'm going to do it.



1. Introduction

2013 marks the anniversary of 20 years of Macmillan investment in information and support services across the UK.

During this period, access to information and support services has changed significantly. Before 1993, when we part-funded the Lynda Jackson Macmillan Centre at Mount Vernon Cancer Centre, Macmillan had little to no experience of developing information and support services. To date, we've invested over £70 million in more than 170 services. We've invested in new-builds and refurbishments as well as specialist roles and posts – creating, sustaining and expanding specialist cancer information and support services across the UK. In 2012, more than 350,000 people nationwide benefited from using these services.

We know how valuable positive experiences of the healthcare system can be. And improving that experience by providing local cancer information and support can make a real difference to a person's quality of life. It can help to improve their physical and mental health, financial situation and ability to manage living with cancer. In fact, there is evidence linking improved quality of life to faster recovery, earlier discharge from hospital and a reduction in the use of statutory services. Research shows us that 87% of people living with cancer want to know more about their disease. However, many do not receive the right information at the right time in the right way.

We've produced this report to contribute to aspects of the 2013 Macmillan Information and Support Professionals' Conference.
The conference, which takes place on 3–4 June 2013, celebrates 20 years of Macmillan information and support services.

The report aims to:

- celebrate the history and development of partnerships and Macmillan-funded cancer information and support services across the UK
- acknowledge Macmillan's first investment

 the Lynda Jackson Macmillan Centre,
 which opened in June 1993
- reflect on key developments, highlight areas of learning and recognise the value these services offer people affected by cancer
- consider the future for Macmillan cancer information and support services through enhanced partnership working.

Looking forward, the final section of this report lays out key strategic activities up to 2015. It also reinforces our intention to work in partnership with services to achieve these.

All people affected by cancer, and their family and carers, will have the information and support they need throughout their cancer journey, so that they can make the best decisions for them about their treatment and their lives.



Working in partnership to change lives

2. Background

Macmillan cancer information and support services are many and varied, but generally are partnerships between a health or social care provider and Macmillan Cancer Support.

The umbrella term 'cancer information and support services' describes the following:

- an information centre in a variety of settings e.g. hospice, hospital or the community
- an information point or pod staffed by a volunteer or professional
- a part-time outreach service provided by the centre in another location, with set hours each week
- a library information service
- a Macmillan-funded or adopted information professional providing a service.

In addition, the following can complement cancer information and support services:

- financial support services including benefits advice
- Macmillan mobile information services
- Macmillan Support Line

- Macmillan digital information services
- Boots Macmillan Information Pharmacists
- Macmillan professionals.

All services have access to free, up-to-date, quality-assured information materials, supplied by us or other organisations as appropriate. These materials are available in printed and digital formats. Some of these materials are available in other languages, as easy-read resources or in audio.

When calculating that there are 171 cancer information and support services, we have used the following definition:

Macmillan cancer information and support services have been developed between Macmillan and a partner organisation.

The service may be delivered through a single post or a managed service with multiple staff and volunteers. When the service or post was initially established, it was funded by Macmillan and/or adopted by Macmillan at a later date.

Did you know?

Boots Macmillan Information Pharmacists

We have developed training for Boots pharmacists and healthcare assistants on the issues that surround cancer. This builds on the specialist training they already receive and helps them to offer more comprehensive healthcare advice on the high street and in local communities. Training has also been developed for No7 consultants on how to support women dealing with the visible side effects of cancer treatment – specifically skincare and make up skills.

3. A short history of Macmillan cancer information and support services

Early development (1990s)

Providing information on recognising, preventing and treating cancer has been a priority for Macmillan since we were founded by Douglas Macmillan in 1911. In the beginning, almoners – renamed as medical social workers around 1960 – gave information and offered financial relief to people affected by cancer.

The first clinical nurse specialist post was established in 1975, with a specific remit to provide information. We then went on to found daughter charities such as Breast Cancer Care, Cancerlink and the British Colostomy Association.³

However, it wasn't until the early 1990s that we made our first significant investment in a dedicated cancer information and support centre. This was the Lynda Jackson Macmillan Centre (LJMC), which first opened its doors in 1993. The LJMC was based on-site next to the Mount Vernon Cancer Centre in Northwood, Middlesex. At the time, Mount Vernon was a regional cancer centre serving a population of two million, and receiving more than 5,000 referrals for specialist treatment each year.⁴

The proposal for a support and information centre at Mount Vernon followed evaluation and research gathered by speaking to local people living with cancer. This included people in active treatment, as well as those who had completed treatment and were members of local cancer support groups. Several studies identified a number of recommendations specifically around improving access to support and education, improving communication and making written information more readily available.⁵

In 1992, when we were asked to provide financial support to the proposed regional cancer support and information centre, we'd had little involvement in providing physical environments specifically for cancer information. Two small community-based services were developed around the same time, one in Liverpool city centre and another in Cinderford in the Forest of Dean. However, they failed to attract enough service users and didn't last.

With little planning experience to draw on, our support for the Lynda Jackson Macmillan Centre was quite hands-off. We left it to Judy Young, the cancer centre counsellor who set up the service, along with the architects, to develop the form and specification of the building. Judy was later involved in developing a quality toolkit for setting up Macmillan information and support services. She also spent many of the early years as an ambassador for Macmillan, speaking to teams and mentoring new services as they were established.

Cancer support services were not unknown in the 90s. The Bristol Cancer Help Centre – which used existing buildings – had been established for more than a decade, while others, such as the Hamar Centre at the Royal Shrewsbury Hospital, had been purpose built. There were other examples of early information and support services in the community, often developed independently. CANCERi in St Albans and Bosom Friends in Hillingdon are two examples.

What distinguished the LJMC from these was its strong location and operational links as an NHS facility with acute cancer services on site. This is a pattern that we followed in subsequent centres. The first generation of Macmillan information and support centres trod the same ground as the LJMC – medium to large, newbuild facilities with a full range of therapeutic and supportive services for individuals and groups, located close to acute cancer services but with independent access.

Although they all shared roughly the same accommodation and service plan, there wasn't a physical template. So the Mustard Tree Macmillan Centre at Derriford Hospital, Plymouth, opened in 1998, looked different to the Robert Ogden Macmillan Centre at St James' Hospital, Leeds. This was despite the fact that they were planned at the same time. Both services have remained at the forefront of development, maintaining a long-term relationship with us.

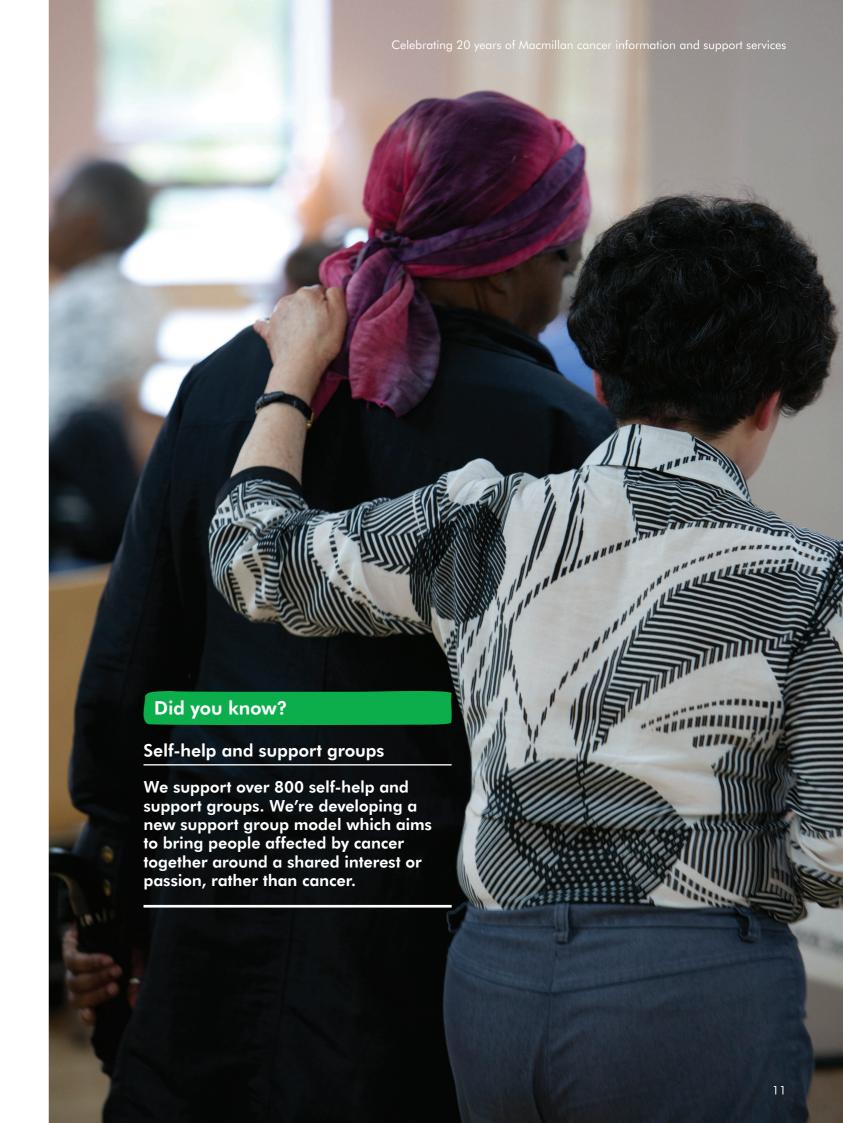
Although the LJMC was admirably inexpensive, large freestanding support centres were costly to build and run. Not all hospitals could justify such a major investment for the size of cancer services on site. There had already been calls for a smaller facility model, capable of being embedded in the acute service itself. Two such centres, at Hastings and Guildford, were completed in 1998.

Throughout the 90s, investment and development was sporadic and opportunistic. It wasn't until 1999 that a more structured approach to service and facility planning for information and support services evolved. This was led by our first head of information services, Catherine Dickens. Catherine commissioned research into local information services, conducted by the British Market Research Bureau (BMRB) in 1999, and again in 2003.

The findings clearly showed that the NHS was a key provider of information, but that other sources including support groups, charities and cancer information centres were also relevant.⁶ People affected by cancer felt that having an information and support service close to a hospital service was important. Users wanted a quality-assured service with a manager to oversee the service. They also wanted volunteers, often with an experience of cancer, to play a key part, particularly in meeting and greeting people using the service.⁷

At the same time, we established a team of UK information consultants. In partnership with our Cancer Environments department, they responded to hospitals' requests to develop services. A further recommendation from the BMRB report was to develop the Macmillan quality toolkit: ensuring quality in Macmillan Cancer Relief information and support services. Launched in 1999, the toolkit set out three levels of facility based on service user need. There was a small information unit of around 50m², a medium-sized information centre of about 150m² and a large model measuring upwards of 250m² – the size of the present LJMC. These models and recommendations for developing the services were further explained in the Information consultants' handbook, which was published the following year, and outlined the core elements of an information and support service.

We also held a small suite of information publications. Our main priority in the mid to late 90s was to avoid duplicating what was already available and to catalogue, inform and fill any gaps that arose. We created the *Directory* of cancer information materials to raise awareness of the range of materials available, and focused on developing information to fill gaps, such as about financial issues.



A strategic approach (2000s)

The 2000s saw a huge expansion in services, led through a UK-wide strategy. There was increased emphasis on developing the quality of the services and the information offered. It was expected that in the future all new partnership information and support services would work to meet Macmillan's vision at the time. This was 'to ensure that people affected by cancer had access to good-quality, comprehensive and appropriate information and support'.8

We asked our partners to adhere to quality indicators, and to report quarterly and annually about their service against the recommendations in the Macmillan quality handbook, published in 1999.

From one or two services a year in the late 90s, the numbers grew to five new services in 2001, nine in 2003, 19 in 2008 and an impressive 22 in 2009. At first, nearly all of these followed the smallest facility model – a compact layout of three or four spaces comprising an open drop-in resource area, a quiet room and an administrative space. In some cases, there was also a complementary therapy room.

Many were built as part of a larger acute service development, usually day oncology, and were accessed from the main reception and waiting areas of the acute unit. Typical examples included centres at the Queen Elizabeth Hospital, King's Lynn in 2001; West Suffolk Hospital, Bury St Edmunds in 2005; and Leighton Hospital, Crewe in 2008. All are associated with Macmillan chemotherapy units.

Fewer medium-to-large centres made it off the drawing board. Cost was certainly a factor, both capital and revenue, as was the business justification for such a major non-clinical facility when NHS resources were focused on clinical priorities. Two that did emerge – Southampton in 2005 and Wythenshawe in 2008 – were both linked-detached centres, umbilically connected to the main hospital. The large freestanding information centre at Belfast City Hospital,

completed in 2006, was an exception. This was not least because it involved recycling a listed 19th century terrace of houses that attracted keen interest from the city's heritage bodies. This almost resulted in a working fireplace in each room.

In June 2003, we published a further appraisal of cancer information and support services, which is still relevant today. It recognised a number of success factors for the development of a service:

- planning a service based on an assessment of need and having adequate and sustainable capacity to deliver an inclusive, holistic service
- creating a non-clinical environment, where people affected by cancer can be supported by a team of paid workers, volunteers, and clinical staff as needed
- creating a service that optimises the physical space available and is not bound by it
- developing in-reach as well as out-reach approaches to ensure a service is networked into its local communities
- creating a service that is integrated and supported by its host and still has an external, user-centred focus
- building capacity through other community agencies to extend reach
- creating a service that builds on existing initiatives and skills available within the host organisation, and optimises the contribution of external agencies and individuals.

The success factors identified demonstrate that being responsive and patient-centred is not just about resource. Creating the right philosophy, environment, attitude and approach is also key.⁹ While embedded centres were convenient for existing oncology patients, they weren't so easily accessed by people outside the acute care system. Providing information in a more publically accessible location led to the first Macmillan centre in a public library, at Warminster in 2004, followed by Carmondean Library, Livingston in 2008.

The layout of public libraries required a different design approach. It needed to be more open, culturally aligned with the library ethos and non-clinical, a compromise in hospitals where infection control respects few boundaries. A number of library developments followed, most notably in Scotland. For example, a continuing partnership with Glasgow Life builds on earlier developments to provide information centres across the city's public libraries.

Even small centres typically cost about £60,000, and not all hospitals can offer suitable space in the right location. We needed a model which would allow information services to be set up on a temporary basis within a larger area, for example a hospital atrium.

We found a solution with the Macmillan Infopod. This used a high-quality, commercial office partitioning system to create a bespoke, standardised, quick-assembly information centre. The pod fits into the public areas of a hospital and costs under half the price of a fixed unit. A drop-in and information display area, admin desk and circular confidential discussion space all fit into about 18m² of floor space. The prototype flexible environment was tested at Lincoln County Hospital in 2007, adjusted after evaluation and launched as a product a year later. It has since spawned several smaller siblings, including the Info-space, the Info-point and other variants suiting just about every space. Since 2009, these have supported a significant number of new information services in health and social care facilities.

Organisational change within Macmillan took place halfway through the decade. Rather than a national team of consultants with a specialist interest in information and support, we formed regional roles for information and support services advisers. This meant merging responsibility for the ongoing development and quality assurance of the 60 established services into our healthcare team. And information service development became increasingly led through the regions.

This links with the increase in the number of new services that opened in the second half of the decade. Some of this rapid growth can be accounted for by the newer, more flexible types of environment that became available. In addition, fewer new-builds were needed, while rapid refurbishment of smaller spaces sped up the development process.

Did you know?

Evaluation

In 2012 we estimated that our information and support services responded to more than 350,000 enquiries. A total of 39% of these were from people with cancer and just over 28% from carers.

Then, in 2008, we merged with fellow charity Cancerbackup. This helped achieve both charities' aims, to 'ensure that across the UK everyone affected by cancer gets faster and enhanced access to high-quality information at every stage of their cancer journey.'10

The merger allowed us to provide far more comprehensive, high-quality and expertly developed information about cancer. Previously, services could only make these resources available to people affected by cancer by paying for them. The merger ensured that the resources became available to everyone who needed them, free of charge.

It also brought other benefits. We were able to expand our phone line to include support as well as information when the specially trained nurses on the Cancerbackup helpline became part of Macmillan. We also acquired 3,000 pages of digital content. Before, our digital content was limited, supplying information on the top 12 cancers, generic issues and financial support only.

About this time the organisation recentralised the management, quality assurance process and ongoing improvement of information and support services by appointing a new head of information and support. We assessed the existing quality systems for the services, taking into account the original Quality handbook.

Following consultation with regional teams, we decided to work in partnership with the Charities Evaluation Services to develop a bespoke Macmillan version of the national Practical Quality Assurance System for Small Organisations (PQASSO) standards. This would be specifically designed to support Macmillan information and support services, as well as professionals. We launched the Macmillan Quality in Information and Support Services (MQuISS) standards in 2012.

The sister standard to MQuISS is the Macmillan Quality Environment Mark (MQEM). The MQEM is a detailed quality framework used for assessing whether cancer care environments – clinical, and information and support – meet the standards required by people living with cancer. The MQEM standards were developed in collaboration with more than 400 people living with cancer, along with other stakeholders including the Department of Health. The programme initially awarded 14 pilot sites across the UK during 2009, and a further 16 in 2010.¹¹ To date, 96 awards have been made.

Did you know?

MQuISS

As of January 2013, 63% of cancer information and support services were implementing or planning to use MQuISS.



Consolidation (2010s)

This period brings together and consolidates learning with an updated strategy to shape the future of Macmillan cancer information and support services.

After 20 years of creating Macmillan information and support services across the UK, the present picture is one of diversity, in both facilities and service delivery. The innovative University College Hospital Macmillan Cancer Centre opened to the public early in 2012 and was the result of a joint venture between Macmillan, other charities and the NHS. We donated our largest ever single sum of £10 million towards the development.

At the heart of the Cancer Centre is the Macmillan Support and Information Service. This contains all the key components of supportive care: emotional support; information; benefits advice; psychological and counselling professionals; complementary therapies; and volunteering. While very large centres are still a relative rarity, the Sussex Macmillan Cancer Support Centre in Brighton is set to open in 2014. Due to a unique set of circumstances, it is the first time Macmillan will have built and retained ownership of an information and support centre.

The second phase of the Glasgow Life project will provide further library-based services in the heart of the local community. The continuing demand for small information centres in hospitals, fixed or flexible, allows information services to be delivered as close to the point of diagnosis and treatment as practical.

Ensuring that all information remains up to date, is evidence-based and is of high quality remains a key priority for us.

At the beginning of this period between 2010 and 2012, we invested in facilitators as part of the National Cancer Information Prescriptions Implementation Programme. This was a partnership between Macmillan Cancer Support, Cancer Research UK and the NHS.¹²

The ambition was to:

- develop a national digital information resource, through partnership working between the NHS and national cancer charities.
- provide easily accessible personalised information at the right time in the right format for people affected by cancer.

During this national programme, information and support centres played different roles, according to the mix of their services and staff, as well as the depth of integration with NHS cancer services. This is not surprising given the diversity across the UK. Some services have significant numbers of staff and volunteers; others are run single-handedly and must close to participate in service or organisational development. To free up managers' time so they can develop their services, we introduced the information and support assistant role in 2012. This was set up with six NHS partner organisations as an 18-month pilot.

Our priority of ensuring quality and consistency across services led us to set up a team of improvement advisers for information and support services in 2013. The team will work across the UK in partnership with our regional service development teams within the MQuISS framework.



4. Looking forward to 2014/2015

Every day, 889 people are diagnosed with cancer in the UK. Today there are two million people living with cancer and we expect the figure to double by 2030.

Our core business is to provide people affected by cancer with the tools, knowledge and support to cope with the impact of a cancer diagnosis. The Department of Health strategy, *The power of information* (2012) states that access to appropriate information to inform decision making is now regarded as a health service in its own right, rather than an add-on service to other treatment and care.¹³

We therefore aim to achieve our vision through collaboration. We want to ensure that all people affected by cancer, and their family and carers, will have the information and support they need throughout their cancer journey, so that they can make the best decision for them about their treatment, and their lives.

The Macmillan strategy for information and support 2012–2015¹⁴ sets out a number of priorities. Only by working together to deliver these will we be able to positively impact the lives of people affected by cancer.

We will do this through:

Integration:

- creating strong links between local partner organisations and other Macmillan initiatives such as the Boots Macmillan Information Pharmacists
- embedding financial and work support advice, guidance and services locally

Innovation:

 ongoing testing of new initiatives and ways of working

Influence:

 working with key stakeholders to ensure personalisation of information and support is part of national and local policy

Improvement:

- working to improve the content of Macmillan information materials
- working with our partners to ensure consistent quality across the UK for information and support services.

Did you know?

Working through cancer

There are 700,000 people of working age who have had a cancer diagnosis. Our Work support route guide helps professionals to have conversations about work. macmillan.org.uk/work

Key strategic activities for 2013

We're engaged in ongoing work to develop new Macmillan cancer and information support environments and services across the UK. And 2013 sees a renewed emphasis on quality and improvement for service delivery.

Our key strategic activities are to:

- implement the Macmillan Quality in Information and Support Services (MQuISS) standards across the UK
- support our improvement team to work with information and support services across the UK
- work together to effectively evaluate the impact of information and support services across the UK
- develop core competencies for information and support professionals
- work together to improve the content of information materials.

We cannot do this alone so continuing to work closely with our partners is, therefore, a priority.

This report was compiled on behalf of the Information, Financial and Work Support team, part of the Cancer Services Innovation directorate, Macmillan Cancer Support.

If you need more information, please email us at **infomanager@macmillan.org.uk**

Did you know?

Walking for health

The Chief Medical Officer recommends at least 150 minutes of moderate intensity physical activity every week for adults, in bursts of at least 10 minutes, including for most people living with cancer walkingforhealth.org.uk

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Cancer is the toughest fight most of us will ever face. But no one should go through it alone. The Macmillan team is there every step of the way, from the nurses and therapists helping people through treatment, to the campaigners improving cancer care.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way call us on **0808 808 00 00** (Monday to Friday, 9am–8pm) or visit **macmillan.org.uk**

To find out how to get involved call **0300 1000 200** (Monday to Friday, 9am-5pm) or visit macmillan.org.uk/getinvolved

Hard of hearing?

Use textphone **0808 808 0121**, or Text Relay. Non English speaker? Interpreters available.

