

Psychological and emotional support provided by Macmillan Professionals: An evidence review

Key findings

- Many people affected by cancer including carers and family members suffer from psychological distress as a direct result of a cancer diagnosis.
- The psychological effects of a cancer diagnosis are often felt long after treatment has finished. Many of these issues are identified too late to prevent costly interventions and unnecessary use of health services. With timely, effective support many psychological problems can be dealt with in a more cost effective manner or avoided altogether.
- Macmillan funded psychological and emotional support services provided by Macmillan professionals play an important role in meeting the needs of people affected by cancer. They promote self management and coping skills, reduce depression, anxiety and pain; and potentially increase survival rates.
- Providing appropriate and timely psychological and emotional support services can save money for health and social care providers and also benefit the wider community in terms of enabling cancer patients to feel well enough to return to work as well as community and social activities.
- Despite these benefits there are still large gaps in services across the UK. There are still cancer patients who never get appropriate specialist psychological support because there is no service to refer them to.

1. What is the need for psychological and emotional support services for people affected by cancer?

i) How widespread is the need?

There are over six million adults suffering from clinical depression and/or chronic anxiety disorders in the UK yet currently only about a quarter receive treatment of any kind.¹

It is estimated that in 2009/10 mental illness cost the UK economy over £105 billion of which £21.3 billion was in health and social care costs, £30.3 billion was in lost economic output and £53.6 billion was the estimated monetary value attributed to the negative impact on quality of life. These costs have increased by 36% since 2002/03.²

Psychological distress in cancer patients is a significant and ongoing problem.³ Emotional and psychological long-term side effects of cancer and its treatment include depression, anxiety, memory problems, difficulty concentrating, sexual problems and reduced social skills.⁴

Although a certain amount of emotional distress is common, particularly around the time of a diagnosis, approximately 50% of patients (150,000 people per year) experience levels of anxiety and depression severe enough to adversely affect their quality of life.⁵ Although psychological issues are more common in the first year after treatment⁴ one third of patients continue to report significant levels of distress well after treatment has been completed.³ Even 10 years on 54% of cancer survivors (over one million people alive in the UK today) still suffer from at least one psychological issue.⁴

Some groups of cancer patients experience higher levels of distress especially those suffering from lung, pancreatic, Hodgkin's lymphoma, brain, head and neck, leukaemia and lymphoma cancers.³ Women, those with young children, those with co-morbidities and those from poorer backgrounds are also more likely to suffer psychological and emotional problems as a result of a cancer diagnosis.⁶

It is also not just cancer patients who suffer psychologically. 67% of carers experience anxiety and 42% experience depression. Of these over three quarters do not receive any support.⁶

ii) What can lack of support lead to?

In addition to negatively impacting on quality of life recent evidence from 25 independent studies shows that mortality rates can be up to 39% higher in cancer patients with depression.⁷

A 2002 American study showed that cancer patients with previous emotional problems are 2.6 times more likely to die within the first 19 months after diagnosis than patients without prior problems. Patients with both emotional problems and physical limitations pre-diagnosis are 7.6 times more likely to die within that time frame.⁸

A study of 199 cancer patients undergoing stem cell transplantation found that significant bouts of depression during hospitalisation predicted higher one and three year mortality, highlighting the importance of adequate diagnosis and treatment of depression.⁹

Neglecting psychological problems exacerbates illness and increases health care costs. When the emotional needs of cancer patients remain unresolved they are more likely to use community health services, visit their GP and spend more time in hospital.¹¹

A recent estimate of the cost of extended bed days due to preventable psychological illness in cancer patients at the Barts and London NHS Trust was £366,000 per year.³⁰

There is also a personal financial impact due to depression and anxiety preventing many people from working. Some lose their jobs, others who are already out of work lose the will or skills to get back into work. Even those who are working have more time off sick.¹⁰

iii) Why does the current provision not meet the needs of patients?

A 2009 study of 442 cancer patients found 40% of those with emotional problems had not sought help. Of those who did, only 50% of doctors mentioned cancer as a possible cause.⁴

Cancer patients often feel abandoned by the health system¹² and are too distressed to seek help. Concern over physical symptoms often masks the extent of psychological distress.³ Many see unhappiness as an inevitable side effect of cancer, not recognising it as depression.⁴

*'It does feel like after your last chemo session you are on your own. It's then when you are not so much supported by nurses/doctors etc, that it hits home what has happened and the 'mental health' element kicks in. That is where I feel support is lacking.'*¹²

Health and social care professionals often lack appropriate assessment skills to identify mental illness and may underestimate the benefits of psychological support.⁵ Psychosocial oncology departments are often understaffed, under-funded and uncoordinated, while primary care staff are over-burdened and can overlook psychological issues.¹¹

*'In hindsight I probably did need support but wasn't aware of it at the time – emotional needs weren't discussed with the nurses doing consultations, I think they were too busy.'*¹²

In order for the current four tier model of psychological support (described in [section 2](#)) to function effectively staff operating at higher levels must be qualified to train up staff at lower levels to ensure that everyone has the appropriate skills to perform their roles at an acceptable level.

Routine screening of cancer patients for psychological problems is not commonplace, most are self referred or referred by medical professionals who notice their distress during clinical care.³ Some staff don't know who to turn to for advice and support for patients and carers in distress.⁵

Emotional support is often provided in a one size fits all format rather than tailored to the individual.¹² Current models of follow up care for cancer patients often fail to respond adequately to patients needs*. Developing personalised holistic care plans is one way to identify and deal with unresolved needs. Individual assessments and care plans also ensure resources can be targeted at those who are most in need.¹³

*'The nurse said to me: 'you can have social services – they can clean for you' but this was not what we needed – our needs were so poorly understood by the medical and nursing profession.'*¹²

2. How are Macmillan professionals helping to meet the psychological support needs of people affected by cancer?

i) The four-tier model

In the UK, the four-tier model of psychological support shown overleaf has been recommended by NICE for all patients with cancer and their families.¹⁴

This model suggests that staff at level two, such as nurses, doctors, and allied health professionals, should be proficient at screening for psychological distress and intervening with techniques such as psycho-education and problem solving.¹⁴

The interventions are targeted at three points during the cancer journey: diagnosis, immediately post treatment and end of life. Different treatment types are more effective at different stages.³

* To combat this Macmillan is currently piloting 15 Health and Well Being Clinics as part of the National Cancer Survivorship Initiative. These clinics are one off educational signposting events point for other forms of after care. Patients are able to access information and advice from health professionals and peers about ongoing self management of their disease, including practical, financial and emotional support. The clinics also raise awareness of local facilities, supportive care and opportunities that are available to them and their families. Early results from the pilots are positive with patients leaving feeling more knowledgeable and more confident about managing their own health, knowing how to cope better and where and who to go to for further help.

The NICE approved four tier model of psychological support

Level	Who should provide it?	What should be assessed?	What is the intervention?
1	All health & social care professionals	Recognition of psychological needs	Effective information giving, compassionate communications and general psychological support
2	Health & social care professionals with additional expertise (including CNS)	Screening for psychological distress	Using standardised screening tools e.g. the Distress Thermometer, HADS etc.
3	Trained and accredited professionals	Assessments for psychological distress and diagnosis of some psychopathology	Counselling and specific psychological interventions such as anxiety management and solution focused therapy, delivered according to an explicit therapeutic framework.
4	Mental Health Specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy.

ii) Macmillan's psychological and emotional support provision

Macmillan proactively develops services which offer high quality psychological, psychosocial and emotional support for people affected by cancer and to influence other statutory and voluntary health and social care providers to do the same. These services are provided indirectly through the funding of Macmillan professionals and directly through the provision of the Macmillan Support Line. (Please refer to [Macmillan Support Line: An evidence review](#) for more information.)[†]

Macmillan works to meet the needs of cancer patients and families at all four levels but primarily focuses on levels one to three. We provide our funded professionals with access to learning and development grants to develop their skills and provide higher levels of support.

Macmillan funded social workers, occupational therapists and appropriately trained clinical nurse specialists (CNS) provide support at level two. Some are qualified in psychological therapies such as CBT and can provide support at level three. All counsellors and psychotherapists provide support at level three and level four support is provided by qualified psychologists and psychotherapists.

Although there is a need for additional posts across all four levels of support, a particular need for additional level three psychological support was identified in the 2004 NICE guidance on cancer and palliative care.⁵ Many level four staff are also delivering care at level 3 in addition to their existing workload, which is neither efficient nor cost effective.

iii) Specialist tools and training

Macmillan provides training to up-skill health and social care professionals to be able to deliver level two and three interventions. These staff then train other colleagues to deliver support at level one, enabling them to focus on more complex cases and make more efficient use of their skills.¹⁵

Although more cost effective in the long run, training up staff at lower levels is still time consuming and outside current role descriptions of most level three and four staff. Macmillan provides the support to facilitate this training in the most efficient manner but ideally wants to see a full provision of staff at all four levels to reduce administrative and training demands on high level staff.

Macmillan funded professionals have access to psychological 'small tools' such as the 'Distress Thermometer' which are currently being developed by SIGOPAC.[‡] Macmillan professionals are

[†] Macmillan also knows that the physical environment can have an impact on how cancer patients feel and respond to treatment. Over the last 30 years Macmillan has funded and planned over 175 specially designed cancer environments in various community and hospital locations to create calming, therapeutic and excellent working environments. The impact of the physical environment has not been included within the scope of this work

[‡] The British Psychological Society special interest group of psychologists working within Oncology and Palliative care.

provided with the training to use them effectively, which ensures patients are assessed at key points along the care pathway and supported quickly and appropriately.

Case Study –The Distress Thermometer^{16 17}

The Distress Thermometer is an assessment tool that covers all domains of care (physical, psychological, social, spiritual and relationships). It uses five questions to help indicate whether the patient is distressed and to what level. It was developed in 1998 by the National Comprehensive Cancer Network in the US, but despite being quick (about 20 seconds) and easy to use, but has not been widely implemented in the UK.

The Macmillan information and support radiographers at Ipswich Hospital NHS Trust (National Cancer Survivorship Initiative pilot sites for assessment and care planning) are available to provide psychological and emotional support to anyone affected by radiotherapy treatment. However results from a recent audit indicated that only 50% of people having radiotherapy treatment had contact with these information and support services and 35% were unaware that any support of this nature was available to them. Therefore it was felt that a tool would be useful for screening everyone attending the department to ensure those who need help receive it.

In a recent pilot the Distress Thermometer successfully identified which patients needed help and support and it has now been adopted as the recommended tool at the trust. There are now several sites using the Distress Thermometer or similar assessment tools in the UK.

The tool is currently on the National Cancer Survivorship Initiative website for use in survivorship pilot sites and Macmillan is currently negotiating for a licence from the National Comprehensive Cancer Network in the US to use the Distress Thermometer more widely. Following feedback from patients the licence application will also see a name change to 'Issues of Concern'.

Macmillan professionals also have access to communication skills training and supervision which improves the effectiveness of psychological and emotional support delivery. These training programmes can be cascaded down through the team resulting in improved patient experience. Ongoing support and supervision is proven to enhance clinical effectiveness of communication skills training, enabling health professionals to better identify psychological concerns.¹⁸

Case Study – Psychological training¹⁹

A four session training package, developed by Dr. Kate Jenkins of the Salisbury NHS Foundation Trust (working with the current NCSI test sites) provides a structured, streamline framework using assessment tools to identify those in distress, assess the severity of the distress, and decide on the appropriate level of intervention.¹⁹

Over three years, analysis of 255 confidence questionnaires completed by participants show a 40% increase in confidence across a number of measures between pre and post course.¹⁹

The three year programme also identified that appropriate assessment and care planning enabled people's needs to be met appropriately and reduced the number of inappropriate referrals to the psychology team.

3. What impact do effective psychological and emotional support services have?

i) Improving the health and well being of people affected by cancer

The benefits of effective psychological support include reduced depression, anxiety and pain, improved self management and coping skills, helping patients feel more in control and improving their quality of life.²⁰

*'Marie [Macmillan psychologist] was outstanding in helping me – she is wonderful. I couldn't have gone through this trauma without her help. MARVELLOUS!'*²⁶

A Canadian study of 89 women with breast cancer found that those who participated in a cognitive behavioural therapy treatment class had less depression, better overall quality of life and fewer psychiatric symptoms post intervention and at two year post intervention follow up.²⁹

Some of Macmillan's clinical psychologists co-facilitate a six week course for people affected by cancer to help them cope with living with cancer once treatment has finished. Recent evaluations using the cancer coping questionnaire (CCQ) have shown a reduction in anxiety and depression amongst patients and a significant rise in participants' cancer coping scores.²¹

Case Study – Improving Access to Psychological Therapy (IAPT)²²

In 2006, two government projects were established in Doncaster and Newham to provide cognitive behavioural therapy services to people suffering from depression and anxiety.

- In the first 13 months 5,500 people were referred to the service and 3,500 have now completed treatment.
- 52% of people who had suffered for six months or more reported recovery and these gains were maintained 4-12 months later. Previous evidence of patients with >6 months duration of depression and anxiety suggests that without intervention only 20% of patients recover.
- At the end of treatment 5% of the group had improved their employment status.
- The self-referral route available through the IAPT project was highly successful at attracting people from harder to reach groups such as people with a disability and ethnic minorities as opposed to general practice referrals.
- The self referral system was more effective at picking up problems such as social phobia and obsessive compulsive disorder compared to general practice referrals.

Communication training and supervision offered to Macmillan Professionals helps to improve the well being and care of patients. A willingness to listen and explain is considered to be one of the essential attributes of care. Effective communication influences wellbeing, pain control, adherence to treatment and psychological health and timely conversations result in improved care.²³

Communication training also increases staff confidence, competence and job satisfaction, which leads to better retention, productivity and improved outcomes for service users.²⁴

ii) Reducing the work load of other health and social care professionals

Health professionals agree that the Macmillan psychological and emotional support services are vital for effective holistic patient care.²⁵ These services help to reduce workloads, enabling health and social care professionals to focus on their core services as demonstrated by the quote below:

*'A service that I as a practitioner could not do without. An essential component of care for cancer/palliative care patients that supports the improvement of patient experience and quality; meets the supportive palliative care agenda; enabled the development of staff in managing psychological issues with patients.'*²⁵

Level three cancer specialist psychotherapists at Luton hospital have enabled consultant clinical psychologists to focus on delivering level four interventions and developing other psychological services. These posts also deliver educational programmes to level two staff to improve their ability to assess the psychological needs of cancer and palliative care patients. Evaluation of the service has been very good with all patients rating their experience of the service as entirely satisfied.²⁶

One study of 313 newly diagnosed cancer patients found that in high risk patients those who received a brief psychological intervention were less likely to develop an anxiety or depressive disorder compared with those who received the usual care. This suggests that psychological care does not have to be delivered by specialists (psychologists/psychiatrists) for it to be effective.²⁷ With the appropriate governance in place the concept of non-specialists performing this therapy frees up time for psychological specialists to concentrate on more complex cases and is potentially more cost effective for the health service.²⁷

There is a shortage of level three posts in the UK and so training level two staff to deliver brief psychological interventions frees up level three staff for more complex cases and enables them to focus on their core responsibilities in a more efficient and cost effective manner.¹⁹

iii) Potential efficiency gains for health and social care

Providing appropriate, timely psychological and emotional support services can potentially save health and social care services money by ¹¹:

- Preventing mild psychological problems developing into more complex problems which require hospital admission to treat.¹¹
- Helping patients achieve better overall psychological and physical health leading to a reduced need for health care services, particularly GP appointments.¹¹
- Improving the willingness and/or ability of patients to adhere to medical advice and demanding treatment regimes and therefore recovering faster.¹¹

A study by the Centre for Economic Performance estimates that the overall gain to society of treating psychological disorders in patients with 10 sessions of cognitive behavioural therapy (costing £750) is £4,700. This includes factors such as earlier return to work, reduced health care visits and improved quality of life.²⁸

A 2001 study of 89 Canadian women with cancer showed a 24% reduction in direct health care costs in those who received cognitive behavioural therapy. Taking into account the cost of intervention this resulted in a net saving of CAD \$47 (£21 at 2001 rates) per person.²⁹ Over the course of the study total savings of \$6,199 (£2,767 at 2001 rates) were estimated. This saving would have been significantly higher if the intervention had been carried out by psychologists or social workers instead of more expensive psychiatrists.²⁹

*'I would emphasise the cost-effectiveness of having a hospital based cancer psychology service because it uses very few resources (no drugs, no medical equipment, no beds) it is actually one of the cheapest services around. It can also produce real cost savings for the hospital in that patients engage better in treatment and need less symptom management, recover more quickly to point of discharge, are less likely to need re-admission and access their CNS less frequently.'*³⁰ (Clinical Oncology Psychologist consulted as part of an evaluation of services by United Lincolnshire Hospitals NHS Trust).

Case Study – Pennebaker paradigm³¹

The Pennebaker paradigm is a written emotional disclosure tool to help patients discuss their feelings and identify any unmet psychological and emotional needs.

In a study of 30 men with prostate cancer those following the technique had on average 5.6 fewer contacts with the health service over a 6 month period. At a cost of £28 per 10 minute consultation (based on 2010 costs³²) savings of £156 per person were estimated. Patients using the tool also reported reduced pain relief and medication use.

Conclusion

Cancer affects people physically, emotionally and financially. It is often the emotional effects which are the most neglected and last the longest after treatment is finished.

Early and appropriate psychological and emotional support can not only improve the health and well being of people affected by cancer but also prove cost effective for health authorities and local communities by potentially reducing visits to the GP, medication use and emergency admissions.

Macmillan supported psychologists have the skills and knowledge to support and treat those people affected by cancer who have been identified as needing, and would benefit from, a psychological intervention. Despite the vital services these posts provide for people affected by cancer there are gaps in service provision across the UK, especially those who provide level three interventions.

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