

## IMPACT BRIEFS

WE ARE  
MACMILLAN.  
CANCER SUPPORT

# PSYCHOLOGICAL AND EMOTIONAL SUPPORT

### What are they?

Macmillan funds Psychological and Emotional Support services that are provided by Macmillan Professionals. These services play an important role in meeting the needs of people affected by cancer.

The services promote self-management and coping skills, reduce depression, anxiety and pain; and can also potentially increase survival rates.

*'Marie (my Macmillan Psychologist) was outstanding in helping me – she is wonderful, I couldn't have gone through this trauma without her help.'*

This Impact Brief is part of a suite of Impact Briefs which provide evidence about the impact of Macmillan's direct and indirect services, available at [www.macmillan.org.uk/impactbriefs](http://www.macmillan.org.uk/impactbriefs)

### Need



Even 10 years after treatment **54%** of cancer survivors still suffer from at least one psychological issue.<sup>6</sup>



Mental illness costs the UK economy over **£21 billion** in health and social care related costs per year<sup>4</sup>

### Reach



Macmillan proactively develops services which offer high quality psychological and emotional support for people affected by cancer.



Macmillan provides training to up-skill health and social care professionals to be able to recognise psychological needs and to deliver effective support.<sup>18</sup>

### Impact



The overall benefit to society of treating patients with 10 sessions of cognitive behavioural therapy is **£4,700**.<sup>32</sup>



Health care professionals agree that Macmillan Psychological and Emotional Support Services are vital for effective holistic patient care, allowing health and social care professionals to focus on their core service.<sup>29</sup>

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# PSYCHOLOGICAL AND EMOTIONAL SUPPORT

## INTRODUCTION

Psychological distress is a significant and ongoing problem for cancer patients, those living with cancer are affected from the time of diagnosis, during their treatment and most commonly in the first year after diagnosis. These mental health needs are often neglected as they are not always recognised and properly understood.

Macmillan Health and Social Care Professionals deliver effective Psychological and Emotional Support services for cancer patients, targeting support at three points in the cancer pathway - at the time of diagnosis, immediately post treatment and at the end of life. Macmillan's services help to free up time for other health care professionals to focus on their core services.

## SUMMARY OF KEY FINDINGS

- **Psychological distress**  
Many people affected by cancer including carers, and family members, suffer from psychological distress as a direct result of a cancer diagnosis.
- **Need for timely psychological support**  
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.
- **Benefits of Macmillan support**  
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.
- **Wider benefits**  
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.

# DETAILED FINDINGS

## 1. What is the issue?

### i) How widespread is the need for psychological and emotional support services?

Between 8-12% of the population experience depression in any year, it is one of the most common mental health disorders in Britain yet only about a quarter receive treatment of any kind.<sup>1, 2, 3</sup>

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.<sup>4</sup>

The Centre for Mental Health recently estimated that a comprehensive roll out of hospital-based liaison psychiatry services could save £5 million per year in an average 500 bed general hospital or £1.2 billion per year nationally.<sup>7</sup>

Psychological distress in cancer patients is a significant and ongoing problem.<sup>5</sup> 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.<sup>6</sup>

According to the 'Parity of esteem' principle, enshrined in law by the Health and Social Care Act 2012, mental health must be given equal priority to physical health. However, there are still many areas where this not yet been realised and the NHS Constitution still does not give equal access to mental health care, with spending on mental health services failing in many areas.<sup>7</sup>

A certain amount of emotional distress is common, particularly around the time of a diagnosis, with psychological issues more common in the first year after treatment, however 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.<sup>6</sup>

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.<sup>5</sup> 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.<sup>8</sup>

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.<sup>8</sup>

### 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.<sup>9</sup>

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.<sup>10</sup>

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.<sup>15</sup>



In 2010 the cost of extended bed days due to preventable psychological illness in cancer patients at the Barts and London NHS Trust was an estimated £366,000 per year.<sup>11</sup>

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.<sup>12</sup>

*'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.'*<sup>13</sup>

**Cancer patient**

*'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.'*<sup>16</sup>

**Cancer patient**

### 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.<sup>6</sup>

Cancer patients often feel abandoned by the health system<sup>13</sup> and are too distressed to seek help. Concern over physical symptoms often masks the extent of psychological distress.<sup>5</sup> Many see unhappiness as an inevitable side effect of cancer, not recognising it as depression.<sup>6</sup>

Health and social care professionals often lack appropriate assessment skills to identify mental illness and may underestimate the benefits of psychological support.<sup>14</sup> Psychosocial oncology departments are often understaffed, under-funded and uncoordinated, while primary care staff are over-burdened and can overlook psychological issues.<sup>15</sup>

In order for the current four tier model of psychological support (described in the section below) 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.<sup>5</sup> Some staff don't know who to turn to for advice and support for patients and carers in distress.<sup>14</sup>

Emotional support is often provided in a “one size fits all” format rather than tailored to the individual.<sup>13</sup> 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.<sup>16</sup>

*‘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?’<sup>13</sup>*

**Cancer patient**

## 2. What is Macmillan doing to address the issue?

### Meeting 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.<sup>17</sup>

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.<sup>17</sup>

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.<sup>5</sup>

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\* To combat this Macmillan runs 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. Results from the pilots are positive with patients leaving feeling more knowledgeable and more confident about managing their own health, improved quality of life with increased ability to manage emotional stress, 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, Hospital Anxiety and Depression Scale 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 the Macmillan Support Line Impact Brief for more information.)<sup>†</sup>

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.

### 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.<sup>18</sup>

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' developed by SIGOPAC.<sup>‡</sup> Macmillan professionals are 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.

<sup>†</sup> 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

<sup>‡</sup> The British Psychological Society special interest group of psychologists working within Oncology and Palliative care.

## Case Study: The distress thermometer <sup>19,20</sup>

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 an audit of this service 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 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.

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. <sup>21</sup>

## Case Study: psychological training <sup>22</sup>

A four session training package, developed by Dr Kate Jenkins of the Salisbury NHS Foundation Trust provides a structured, streamlined framework using assessment tools to identify those in distress, assess the severity of the distress, and decide on the appropriate level of intervention.

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.

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 is the impact of effective psychological and emotional support services?

#### 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.<sup>23</sup>

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.<sup>24</sup>

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. Evaluations of the service 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.<sup>25</sup>

#### Case Study: Improving Access to Psychological Therapy (IAPT)

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.<sup>27</sup>


Communication training also increases staff confidence, competence and job satisfaction, which leads to better retention, productivity and improved outcomes for service users.<sup>28</sup>

## ii) Reducing the workload 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.<sup>29</sup>

These services help to reduce workloads, enabling health and social care professionals to focus on their core services.

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. The evaluation of the service has been very good with all patients rating their experience of the service as entirely satisfied.<sup>30</sup>



*'The psychological support service is a service that I as a practitioner could not do without. It is an essential component of care for cancer and palliative care patients that supports the improvement of patient experience and quality, meets the supportive palliative care agenda, enables the development of staff in managing psychological issues with patients.'*<sup>29</sup>

**Cancer care professional**

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.<sup>31</sup> 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.<sup>31</sup>

There is a shortage of NICE level three posts in the UK, so training NICE 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.<sup>22</sup>

## 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:<sup>15</sup>

- Preventing mild psychological problems developing into more complex problems which require hospital admission to treat.<sup>15</sup>
- Helping patients achieve better overall psychological and physical health leading to a reduced need for health care services, particularly GP appointments.<sup>15</sup>
- Improving the willingness and/or ability of patients to adhere to medical advice and demanding treatment regimes and therefore recovering faster.<sup>15</sup>

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.<sup>32</sup>

*'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.'*<sup>11</sup>

**Clinical Oncology Psychologist**

(consulted as part of an evaluation of services by United Lincolnshire Hospitals NHS Trust).

## Case Study: Pennebaker paradigm <sup>33</sup>Error! Bookmark not defined.

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 costs<sup>34</sup>) 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.

Macmillan continues to fund psychological support services and needs more charitable donations to fill gaps in service provision across the UK. Go to [www.macmillan.org.uk/donate](http://www.macmillan.org.uk/donate) or call 0300 1000 200 to make a donation.



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