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CANCER SUPPORT

# SOCIAL WORKERS

## What are they?

Macmillan funded Social Workers support people affected by cancer to exercise greater choice and control at all stages of their care pathway.

Social workers provide holistic support that enables those living with cancer to have increased independence and an improved quality of life. They also provide effective emotional and psychological support for cancer patients, their family members and carers.

*'I just wanted to thank you for the help you gave my daughter and I when my husband was in the hospital ward. Unfortunately he has since died but with your help he had two days in the hospice before he died...and we were able to be with him and have some time together.'*

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



**51%** of people living with cancer think that service provision to help with emotional aspects of cancer is important, rating this above medical and practical aspects.<sup>6</sup>



Over **40%** of people with cancer do not feel they are being given enough help from health and social services after discharge from hospital.<sup>7,9</sup>

## Reach



In 2014 Macmillan reached and helped almost **28,000** people through Macmillan social workers.<sup>18</sup>



There were **167** Macmillan social worker posts in December 2014.<sup>32</sup>

## Impact



A study of 3 Macmillan Social Work Services found that they can help to free up the capacity of healthcare professionals - this translated to productivity gains of between **£4,989** and **£32,165** per year.<sup>30</sup>



Setting up systems for the early identification of support needs can both improve patient outcomes and generate economic benefits for the healthcare system.<sup>30</sup>

<http://www.macmillan.org.uk/impactbriefs>

## INTRODUCTION

Macmillan Social Workers support people living with cancer, giving them greater choice and control at all stages of their care.

Social Workers funded by Macmillan offer holistic support, including effective emotional and psychological support, which can lead to increased independence and improved quality of life for cancer patients. In addition, Social Workers also support the family members and carers of those living with cancer.

## SUMMARY OF KEY FINDINGS

### **The financial cost of cancer social care needs**

People with cancer have complex and wide ranging health and social care needs that vary depending on the type of cancer, patient profile and stage of cancer journey. However over a third of people with cancer do not feel confident about how and where to access social care and support.

These needs are often inadequately dealt with by health professionals due to lack of specialist skills and capacity to manage these needs appropriately. Care for many people with long term conditions has traditionally been reactive, unplanned and episodic. This has resulted in heavy use of secondary care services.

### **Holistic support from Macmillan social workers**

Macmillan funded Social Work Services support service users to exercise choice and control at all stages of the care pathway. Holistic support enables service users to have greater independence and improved quality of life due to being able to return home more quickly and being able to access appropriate help and care at home or in their preferred places of care.

These services also provide effective emotional and psychological support for cancer patients, their family members and carers help people deal with cancer and can also free up other health care professionals to focus on their core functions.

### **End of life service**

The end of life care service is particularly valued because although the majority of people want to die at home, less than 30% of cancer patients do so. Cost effective interventions by social care workers can fast-track discharge of end of life care patients and allow them to die in the preferred place.

# DETAILED FINDINGS

## 1. What is the issue?

Cancer incidence is increasing and people with cancer are surviving longer due to better treatment. There are currently 2 million people living with cancer in the UK and this number is increasing at an average of 3% per year. If this trend continues there will be 4 million people living with cancer by 2030.<sup>1</sup> This will lead to a substantial growth in the need for social care support for cancer patients and their carers and families.

Cancer patients have specific and complex social care needs due to the length and nature of treatment, such as the impact of treatment on mobility, on their ability to perform daily tasks, the emotional effects of diagnosis and treatment, as well as carer support needs.<sup>2</sup>

The social care and support needs of those living with cancer include the need for emotional support, help with personal care such as bathing and dressing, advice on work and financial support, help inside and outside the home such as cleaning and shopping, practical aids such as wheelchairs and help to care for children and other dependents such as older relatives.<sup>3</sup> People living with cancer have a range of needs at different stages of the patient pathway, which can vary according to age, gender and socio-economic status.<sup>4</sup>

There is currently a lack of awareness of the ongoing social support that people living with cancer require in order to improve their health and wellbeing and manage their disease. Care for many people with long term conditions has traditionally been reactive, unplanned and episodic. This has resulted in heavy use of secondary care services. Social services are there to help patients when their condition reaches crisis point, but often fail to provide the on-going, co-ordinated support needed to prevent such crises from happening in the first place.<sup>5</sup>

51% of people living with cancer think that service provision to help with emotional aspects of cancer is important, rating this above medical and practical aspects.<sup>6</sup> Yet cancer patients are not getting access to the social care they need. Over 40% of people with cancer do not feel they are being given enough help from health and social services after discharge from hospital and many do not feel confident about how and where to access social care and support.<sup>7,9</sup> In addition, family and relatives of those living with cancer can also be emotionally affected by the diagnosis and physical effects of the treatment that patients experience<sup>8</sup>.

### Inconsistencies in provision of social care

More also needs to be done to ensure patients across the country receive consistent access to the care they need. The 2014 National Cancer Experience Survey, questioning over 70,000 cancer patients across England, found significant national variation in the proportion of patients that were given enough care and help from health or social services after leaving hospital. At the worst only 23% of patients received the care they needed from their NHS Trust and 85% at best.<sup>9</sup>

The number of agencies involved in planning and delivering services makes collaboration difficult. Social services are neither well known nor well understood by other health care professionals and they might not know how to access social workers, leading to delays in getting assessments of social care need and subsequent access to services.<sup>10</sup>

Cancer is still seen as an acute disease which means that services are not targeted at monitoring cancer patients in the long term and supporting them to live well following diagnosis and treatment.<sup>11</sup> Identifying and meeting the needs of cancer through medical rather than social sources defines the problem as medical, and not personal or social. This means that the contribution of social services and support available may be overlooked, such as welfare benefits advisers who are considered by patients

to be extremely beneficial.<sup>12</sup> There is a lack of adequate signposting to available social care support for cancer patients.<sup>13</sup>

Local authorities (LAs) do not traditionally perceive cancer as a social care issue and therefore cancer specific social care provision is rarely provided due to disagreements over funding and cancer being assessed as part of mainstream services.<sup>2</sup> This is still the case despite a more positive funding backdrop where the budget allocation to local authorities for services that benefit health and social care was increased by 38% in 2013/14.<sup>14</sup>

Local authorities have also expressed concern that their staff may not fully understand the needs of people affected by cancer to assess them effectively. Assessors need training to understand the needs of people with different long-term conditions such as cancer.<sup>2</sup> Assessment and discussion of patients' needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as at diagnosis; at commencement, during, and at the end of treatment; at relapse; and when death is approaching). A unified approach to assessing and recording patients' needs should be adopted, and professionals should carry out assessments in partnership with patients and carers.<sup>15</sup>

There is robust evidence that with preventative social care interventions unplanned hospital admission can be delayed or avoided and cancer patients can live independently for longer.<sup>16</sup>

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

In December 2014 Macmillan had 167 social workers active in post across the UK<sup>17</sup> and in 2014 reached almost 28,000 people through Macmillan social workers.<sup>18</sup>

Social workers offer a variety of support as listed below, whilst each social worker may have a slightly different focus of activity with clients. Common areas of work include:<sup>19</sup>

- Providing psychosocial and emotional support to individual patients and their families
- Facilitating and coordinating discharges
- Providing benefits advice or referring patients for benefits advice if there is a welfare rights service available locally
- Helping those with cancer and their families to talk to the children involved and/or in very practical ways helping to organise child care
- Supporting carers
- Providing advice and support to the individual and their family on a range of difficult complex issues which could include finance, housing and safeguarding issues.

Macmillan social workers (alongside a smaller number of Macmillan family support workers) work with community and social services agencies to help people manage the social and practical problems of living with cancer, supporting cancer patients from diagnosis through to post-bereavement, often involving complex cases. The role also involves providing information and resources to individuals, patients and other professionals, pre- and post-bereavement support for children and families, advocacy, development of services, training and education of other professionals, agencies or volunteers and relationship building and cross agency work.

Macmillan social work services are often located within multi-disciplinary teams and work closely across health and social care settings to ensure that patients receive appropriate support. This often includes facilitating timely hospital discharge, arranging and implementing care packages, coordinating NHS Continuing Healthcare assessments, preventing avoidable admissions to hospital,<sup>20</sup> and offering more

complex psycho-social support. Services are designed and delivered according to local need and where appropriate social workers offer specialist support, for example with complex cases, palliative care or bereavement services.

All the Social Work Services we studied emphasise supporting choice and control among service users. This happens at all stages of the care pathway. The holistic approach in ascertaining service user needs allow them to have greater independence and improved quality of life due to being able to return home more quickly<sup>21</sup> and being able to access appropriate help and care at home or in their preferred places of care.

By supporting preferred places of care conversations, including end of life care, the services enable service users to exercise choice and control. For example, the Northampton Social Care Coordinator facilitated 56 preferred places of care choices in 2010.<sup>22</sup>

### 3. What is the impact of effective social workers?

#### i) The impact on health and wellbeing of people living with cancer

Evidence has also shown that interventions focused on improving quality of life for cancer patients in advanced stage of disease and delivered by professionals such as social workers leads to significant improvement in emotional, spiritual and social (especially in relation to financial and legal issues) wellbeing.<sup>23</sup>

Research shows that the emotional support provided by social workers improves psychological health and other psychiatric symptoms for cancer patients<sup>24</sup>. Additionally, this type of proactive service improves outcomes for patients both in terms of getting the help they need quicker, and improving psychological status. This can result in economic outcomes through a reduction in the uptake of inappropriate services. The role also has an impact on increasing the quality of life and wellbeing for patients and their families<sup>25</sup>. Specifically one study shows the benefit to family carers in terms of improving quality of life, and reducing the perceived burden of patients' symptoms and their care tasks<sup>26</sup>.

Access to basic social care services not only enhances someone's quality of life but is also vital if people are to have a genuine choice at the end of life. Services offered might include:

- Help with personal care such as washing, cleaning teeth and dressing
- Assisting someone in and out of bed or helping them to turn over in bed
- Meal preparation, shopping, prescription collection
- Carer support, to help a carer go out and complete tasks away from the home, or have a break to help them continue with their caring role
- Small tasks around the home, such as responding to mail, putting the rubbish out, pet care

Help with these relatively simple things, at such a difficult time, can reduce the pressure felt by families and carers and help them provide the care their loved one needs to stay at home.

However, despite the significant difference social care can make, too often people are not given the opportunity to access it.<sup>39</sup>

One study of the impact of a social care worker in Northampton found that the provision of this service enabled patients to have greater independence, reduced their anxiety and stress and ultimately led to an improved quality of life.<sup>22</sup>

An evaluation of a cancer supportive care project has shown that providing support, information and advocacy to patients with a diagnosis of non curative cancer encouraged self management and reduced the feeling that medical input was necessary or appropriate until the need for intensive care became undeniable.<sup>27</sup>

A social work component within a structured Multi-Disciplinary Team (MDT) can result in improvements in the social domain and improvements in overall quality of life for patients with advanced cancer undergoing active treatment.<sup>28</sup>

For example, the Social Work Team at Mount Vernon Regional Cancer Centre provided 325 episodes of emotional support in 2010. This included helping the service users and their families cope with the cancer diagnosis and/or coming to terms with and planning for death; helping to plan for their children's future; dealing with any employment, financial or housing issues.<sup>22</sup>

Research elsewhere demonstrates that the provision of emotional and psychological support to family members and carers can increase their quality of life and wellbeing, and can reduce the perceived burden of patients' symptoms and their care tasks.<sup>29</sup>

### Case Study: Macmillan Social Worker

A 58 year old woman was diagnosed with advanced lung cancer. She was the mother of two adult sons and a foster parent to 3 foster children. She was absolutely shocked at her diagnosis and responded with a fighting attitude that came across as aggressive to others. There were great tensions in the family. She was concerned about one of her sons who had been a self-harmer. Two of the foster children had learning difficulties.

The Macmillan social worker enabled the family to support the children - to access psychological support for the son and play therapy for the children. They developed a plan for what would happen to the foster children. As the illness progressed the mother moved in with her other son and the Macmillan social worker liaised with the clinician regarding pain relief. The Macmillan social worker continues to support the surviving husband and daughter.

#### ii) Potential cost savings for local health and social care economies

A study of 3 Macmillan Social Work Services found that they can help to free up the capacity of healthcare professionals to focus on their core clinical workloads. This translated to productivity gains of between £4,989 and £32,165 per year.<sup>30</sup>

Research shows that setting up systems for the early identification of support needs can improve outcomes for patients as well as generate economic benefits for the healthcare system<sup>31</sup>. Our economic evaluation identified clear examples of Social Workers taking a proactive approach in the early identification of client needs through effective engagement with patients and with hospital- and community-based health and social care professionals. This speeds up the process of coordination and facilitates the implementation of bespoke care packages.<sup>30</sup>

All Social Work Services adopt a holistic approach to assessing service user needs and play a critical role in organising additional non-health services and support e.g. practical support at home such as a dog walking service.

## Case Study: Cost Savings<sup>22</sup> Mount Vernon and Northampton

Through early identification and effective coordination, Social Work Services generated savings of between £33,904 (Mount Vernon) and £104,646 (Northampton) in a year through reducing delayed discharge. In the absence of such services, patients with specific and complex needs would have been referred to the generic Hospital Discharge Team, where it could take up to five days to be attended to.

The Northampton service generated £44,940 of savings by helping to prevent 10 unnecessary hospital admissions in 2009-2010. The Specialist Palliative Care Social Worker in North Lincolnshire contributed to £383,106 in costs avoided for a range of local services by preventing unnecessary school exclusions of children whose parents are dying or have died from cancer.

## Case Study: Return on investment<sup>30</sup>

Each new Cancer Information and Support service requires an initial investment, which Macmillan often provides. Looking at the return on investment on an annual operational basis, excluding start up costs, every £1 invested in 6 evaluated Macmillan services generated between £0.74 and £18.05 of monetised benefits to service users, and between £0.15 and £3.38 of monetised benefits to the healthcare system.

Macmillan helps to fund and provide social workers to help people living with cancer and their families. Typical costs for 2014 for a Band 4 social worker or family support worker are listed below.

### Cost of a Macmillan Social Worker or Family Support Worker<sup>32\*</sup>

Time period	Cost
1 Day	£107
1 Week	£537
1 Month	£2,327
1 Year	£27,925

\*For more detailed costs of these and other Macmillan services see [be.macmillan.org.uk](http://be.macmillan.org.uk) to download The Cost of Macmillan's Services fact sheet.

Social care interventions to support people living with cancer in the community who have low or moderate social care needs can help them to manage their own conditions and remain independent, potentially preventing emergency admissions to hospital if health gets worse.<sup>33</sup>

Our primary research with Clinical Nurse Specialists (Cancer) (CNS) and community nurses found that a Macmillan Social Work Service can help save them between 2 hours and 10 hours per patient, depending on the level of complexity. For example, bereavement support can be particularly time-consuming. This allows them to focus on their clinical workloads and therefore contributes to the NHS 'releasing time to care' initiative<sup>34</sup>. We identified productivity gains for healthcare professionals of

between £4,989 (Northampton) and £32,165 (Mount Vernon) per year as a result of Macmillan Social Work Services.<sup>22</sup>

Care and support have a key role to play in ensuring that society has a diverse and effective workforce, a healthier, less dependent population, lower benefits bill and less demand on health services.<sup>35</sup> This will lead to cost savings in the economy and on health services including social care costs, which are predicted to rise from £6.3 billion to £11 billion between 2002-03 and 2022-23.<sup>36</sup>

Research shows that increases in emergency hospital admissions in older people partly reflect a lack of availability of appropriate social care.<sup>36</sup>

### End of life care

Macmillan social workers coordinate and facilitate discharge, working with other professionals to enable people at end of life to die at home or helping cancer patients with complex needs to remain at home.<sup>37</sup> The National Audit

Office calculates that enabling more people to die at home

could have significant economic benefits for the health service. For example reducing admissions by 10% and the average length of stay by three days could save health authorities £104 million per year.<sup>38</sup>

There is only one chance to get the care right for someone at the end of their life. Yet the system is not sufficiently equipped to allow individuals to choose where they want to die. Recent analysis shows that 91% of cancer patients in England who die in hospital wanted to die elsewhere, with 65% wanting to die in their own homes. Currently, only 29% of people with cancer are able to be at home when they die.<sup>39</sup>

However, one pilot in Doncaster, which trialled the use of a specialist end of life care social worker, enabled 51% of people in end of life care to die at home.<sup>40</sup>

*'I just wanted to thank you for the help you gave my daughter and I when my husband was on the hospital ward. Unfortunately he has since died but with your help he had two days in the hospice before he died...and we were able to be with him and have some time together.'*<sup>40</sup>

**Carer of a patient who chose to die in a hospice rather than at hospital.**

*'The Social Work Team save a huge amount of time for our doctors and nurses. Particularly by supporting the funding issues, they ensure fast track funding. Without the Team we'd be having to source and commission the care, which would take time. People in need of continuing healthcare funding would need help with the commissioning of care via sourcing private agencies etc.'*<sup>30</sup>

**Hospice worker**

## Case Study: Macmillan Specialist Palliative Care Social Worker – North Lincolnshire<sup>41</sup>

During 2010 this post helped 238 clients and their families. This support:

- Alleviating the emotional and psychological side effects of cancer leading to improved quality of life
- Enabled service users to exercise choice in deciding preferred places to die.
- Improved outcomes for families, particularly those with children, both pre and post bereavement.
- Generated a conservative estimate of **£28,997** in productivity gains by enabling healthcare professionals to focus on core clinical functions
- Created savings of up to **£383,106** by preventing 6 children from being excluded from school

In generating the above benefits, the service:

- Required **£1,000** in set up costs
- Has average annual operational costs of **£48,068**
- Applying a return on investment (ROI) calculation to the monetised costs and benefits shows that on an annual operational basis every **£1** invested by the NHS and the local authority in the service generated **£0.60** of monetised benefits to the healthcare system and **£7.97** to other local services.

## Case Study: Macmillan Social Care Coordinator – Northampton General Hospital<sup>22</sup>

During a 12 month period across 2009-10 this post helped 228 clients. This support Helped service users return home more quickly by reducing delayed discharge.

- Helped service users return home more quickly by reducing delayed discharge.
- Enabled service users to have greater independence, to exercise choice and to enjoy improved quality to life due to being able to access appropriate help and care in their preferred places of care.
- Created savings of **£104,646** as a result of saving 326 excess bed days by reducing delayed discharge
- Created savings of **£44,940** saved as a result of avoiding 10 hospital admissions
- Generated productivity gains of up to **£4,989** by enabling healthcare professionals to concentrate on their core clinical tasks

In generating the above benefits, the service:

- Required **£2,513** in set up costs, paid for by the Northampton General Hospital NHS Trust in 2008.
- Has average annual operational costs of **£69,089**, including an annual 'innovations budget' of £16,000 to spend on improving services to people living with cancer and their families.

Applying a return on investment (ROI) calculation to the monetised costs and benefits shows that on an annual operational basis every **£1** invested in the service by Northampton General Hospital NHS Trust and Macmillan Cancer Support generated **£2.24** of monetised benefits to the healthcare system.

# CONCLUSION

People living with cancer have complex and wide ranging care and support needs, which often result in them spending unnecessary amounts of time in hospital. Unfortunately the majority of health professionals do not have the skills or capacity to deal appropriately with these needs.

Macmillan funded social workers are specialist in this area and can offer a one-stop shop service, co-ordinating appropriate, effective care in an efficient manner which not only saves money for the NHS but also provides patients with a more tailored service.

The end of life care service offered by Macmillan funded social workers is particularly valued with many families expressing their gratitude and thanks for enabling their loved ones to die in their preferred place.

Macmillan continues to fund and support Social Workers and urgently needs more charitable donations to keep these services supporting cancer patients and their families. 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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