



## What are they?

Macmillan Support Workers work as part of the cancer care team alongside registered practitioners to improve care for people with cancer. They work with other professionals and provide support by dealing with non complex tasks to allow registered practitioners to focus their expertise on managing the complex care needs.

They provide coordination of care to people mostly after cancer treatment, who can be enabled to self-manage their own care with support, with open access back to the MDT.

*“My Macmillan Support Worker has been a constant line of support to me. She has been on hand to assist with my return to employment and guide me through the emotional upheavals that come with it. She has directed me to the right channels for financial benefits and assisted with referrals to various clinics I would be lost without her.”<sup>1</sup>*

**Cancer patient**

## Need



Emotional needs are particularly prevalent amongst people with cancer, but the support they need can often be difficult to access and often lacking.<sup>1</sup>



Specialised clinical staff are often taken away from direct care by non complex tasks that could otherwise be picked up by colleagues.

## Reach

Please note these figures relate to level 1 and 2 interventions carried out in the One-to-One Support service pilot. Support Workers carried out the vast majority of these interventions.



In 2014, 28 Support Workers achieved **17,582** contacts with patients made through Macmillan One-to-One Support pilot, and supported **4,396** unique cancer patients.<sup>6</sup>

## Impact

Please note these ratings relate to the total One-to-One Support service pilot. Support Workers make up a large part of the service.



The evaluation of One-to-One Support Pilot revealed that patients rated the quality of care they received through Macmillan One-to-One Support as **9.3** out of **10**.<sup>1</sup>



**89%** of cancer patients said they did not have any other support need following an interaction with Macmillan Support Worker.<sup>1</sup>

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)

[www.macmillan.org.uk/impactbriefs](http://www.macmillan.org.uk/impactbriefs)

# MACMILLAN SUPPORT WORKERS

## INTRODUCTION

New analysis has shown that the number of people living with cancer in the UK has risen by 400,000 people in the last five years – taking the total number of people living with cancer in the UK to 2.5 million. Macmillan estimates that currently there are two million people living with cancer in England, 220,000 in Scotland, 130,000 in Wales and 63,000 in Northern Ireland.<sup>28</sup>

We know that people are now surviving longer. Macmillan estimates that median survival time for people diagnosed after 2007 in the UK is close to 6 years, although survival rates vary significantly for different cancers.<sup>34</sup> For half of people diagnosed with cancer in England and Wales the median survival was at least ten years in 2010-2011.<sup>29</sup>

But the number of people being diagnosed every year is increasing and set to hit 1000 a day in the UK by the end of 2016.<sup>30</sup> Also, hospital admissions are increasing.<sup>31</sup>

The challenge is about living with cancer as well as about surviving with it.

Supporting people living with the consequences of cancer and its treatments, as well as other conditions can be challenging. One in two are living with other co-morbidities, and one in four suffer from the effects of treatment. Worry about recurrence can lead to anxiety so people need to be empowered to manage anxiety and cope with the uncertainty.

Evidence, from the National Audit Office<sup>32</sup> and the Picker Institute<sup>33</sup>, suggests that in some cancers only half of patients benefit from the current follow-up system. While support is generally good during the diagnosis and treatment stage, the real gap in care appears to be during the aftercare stage of the care pathway, for people with consequences of treatment, and on diagnosis of metastatic disease. So we know that the cancer care pathway needs to be redesigned to support people effectively alongside the workforce that supports it.

The increasing number of people living with a cancer diagnosis, and the complexity of need, coupled with a variable and uncertain workforce supply and testing financial environment, means Macmillan's challenge is to ensure that the delivery of care and support is high quality, person-centred, integrated and cost effective.

The current system of follow-up is not meeting people's needs and will not cope in the future. So, we need to think differently about 'cancer care teams', as being made up of cancer specialists, non cancer specialists, their carers, people themselves taking an active role and to include the wider community, who support them across the whole cancer pathway, tailoring support according to individuals needs.

Currently not all people affected by cancer get access to a Clinical Nurse Specialist (CNS) or a Key Worker, which we know makes a difference to patient reported outcomes and experience. We also know that current models of follow-up are unsustainable. Macmillan has been working across the UK testing new ways of working and to develop solutions to these issues. Redesigning the cancer care pathway, redesigning the workforce and how it

supports the cancer care pathway and developing new models of aftercare are seen as some of the solutions.

Macmillan has been testing new roles that work alongside the existing cancer workforce across the UK. This Impact Brief focuses on the role of the Support Worker. The role has been piloted as part of a National Evaluation called One-to-One Support, but other local evaluations and learning has also been drawn on.

The pilot of One-to-One Support involved working with 16 sites across the UK. The aim of One-to-One Support Workers is to enable people living with cancer with non-complex needs to self-manage. This helps registered clinicians focus on supporting those with complex needs.

## SUMMARY OF KEY FINDINGS

- **Support for people with a cancer diagnosis after treatment**  
Macmillan Support Workers interact directly with people affected by cancer. They provide emotional and practical support, both face-to-face and through other means of communication (such as telephone or email). They also help cancer patients navigate the health and social care system, signposting to existing support in the community.
- **Personalised care – identifying and addressing unmet needs**  
Macmillan Support Workers actively work with patients to identify and address concerns of most importance to people after a cancer diagnosis and help them take control of their care using for example Holistic Needs Assessment and inputting into care plans.
- **Implementing the Recovery Package and redesign of follow up**  
Establishing Support Worker roles has created capacity to enable teams to implement the Recovery Package and redesign follow up. The team make a decision about the best form of aftercare based on the needs of each individual
- **Optimisation of resources**  
Support Workers help Clinical Nurse Specialists (CNSs) and other healthcare professionals to use their skills where it is most needed. They take on the less complex aspects of support, allowing registered practitioners to dedicate more time to patients that require their expertise.

# DETAILED FINDINGS

## 1. What is the issue?

### Improving care for people living with cancer

In recent years, there has been an increasing recognition of the needs of people following cancer treatment. The current system does not meet all of the needs of people with cancer, especially when they finish initial treatment for cancer. This is due to many interdependent factors.

#### The importance of post-treatment patient experience

All cancer strategies across the UK recognise the importance of maintaining a person-centred service that ensures excellent levels of patient experience.<sup>7,11,12,35</sup>

Macmillan knows that people living with cancer want to be:

- supported to regain as normal a life as possible
- given advice about how to minimise their risk of developing further cancer-related problems
- given advice about possible signs of recurrence or long-term effects of treatment
- able to re-access specialist services without delay should they need to do so<sup>26</sup>

Also, the importance of good patient experience is acknowledged by the increasing number of patient experience surveys that are being developed. In addition to the more established *Cancer Patient Experience Survey (CPES)* in England (2010) and Wales (2013), Northern Ireland also launched its first *CPES* in 2015 and Scotland, which has recently launched the survey, will publish the findings of its first *CPES* in late 2016.<sup>15</sup>

As people live longer after a cancer diagnosis it is important to develop a service offer that supports people throughout their journey.

Yet, evidence highlights gaps in current service provision, which does not adequately and fully address the needs of people affected by cancer.



*'Medical professionals often speak in jargon. Our Support Worker helps us to understand what we are being told.'*<sup>20</sup>

**Cancer patient**

#### Unmet needs

The 2014 National Cancer Patient Experience Survey highlighted the requirement for the introduction of support such as the One-to-one Support Implementation Project, including

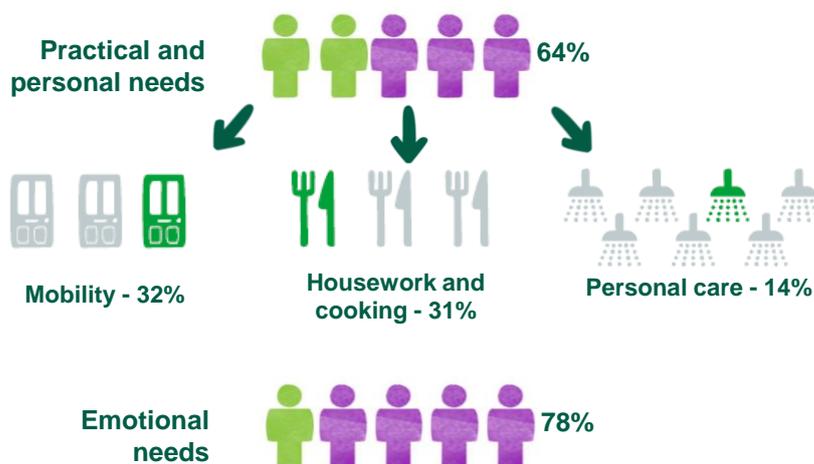
- only 59% of patients in England, 51% in Wales and 66% in Northern Ireland said that hospital staff gave them information about how to get any benefits they may be entitled to
- only 61% of patients in England, 59% in Wales and 69% in Northern Ireland reported that they were definitely given enough care and help from health and social services after leaving hospital – a figure that has declined by 1% in each of the last two surveys

- only 63% of patients in England, 65% in Wales and 75% in Northern Ireland reported that different people (e.g. GPs, hospital doctors/nurses, specialists and community nurses) treating and caring for them always worked well together to give them the best possible care
- only 22% of patients in England and Wales, and 21% in Northern Ireland said they had been offered a written health assessment and care plan – in England this is a slight decrease from the high of 24% recorded in the 2012 survey<sup>24,35,38</sup>

As part of the evaluation of Macmillan One-to-One Support, people living with cancer were asked to feedback on their experience of the health sector prior to accessing the service roles, in order to better understand the overall picture regarding support needs

The evaluation showed that family and friends were the main providers of practical support (85% and 51% respectively). Only 9% said they received support from ‘another’ source, which includes NHS and support groups.<sup>1</sup>

Other research by Macmillan also identifies that practical and emotional needs are particularly prevalent for people living with cancer. 64% of people with cancer report practical and personal needs, which have a significant impact of people’s ability to carry out everyday tasks, yet almost one in three say they do not receive enough support. Emotional needs are also highly prevalent, with 78% of people with cancer reporting emotional needs. Still, almost half of them (45%) do not receive enough support.<sup>19</sup>



Macmillan Cancer Support. Hidden at home. 2015. London

The evaluation of Macmillan One-to-One Support pilot showed that unmet emotional and psychological needs were of particular concern for people living with cancer. Many people living with cancer supported by the Macmillan One-to-One Support pilots pointed out that help dealing with emotional aspects of cancer is the key element in their care, as well as the one they struggle the most with.<sup>1</sup>

In a number of pilot sites the Macmillan evaluation also found that many palliative care patients facing emotional and psychological issues were not able to receive support if they did not qualify for specialist palliative care.<sup>1</sup>

In their experience with Macmillan One-to-One Support, people using the service raised a wide variety of concerns, ranging from emotional to practical:

- Lack of access to support groups (31%)

- Anger and frustration (31%)
- Difficulty making plans (30%)
- How partner was coping (30%)
- Diet and nutrition (30%)
- Sweating (29%)
- Lack of access to complementary therapies (29%)<sup>1</sup>

These are all concerns which heavily impact patient experience throughout their cancer journey.

The Support Worker role as part of the wider cancer care team can improve access to support to address these needs.

### **Person centred support**

The concept of person centred care continues to gain prominence and has the potential to significantly impact on health and social care systems. Shared decision making and self – management support are two of the key elements that underpin person centred care. A recent Health Foundation report highlights the significant impact that these can have on wellbeing, and effectively supporting people to live with long-term conditions.<sup>25</sup> The report also highlights that while person-centred care has become one of the major goals of health policy on all four countries in the UK, slow progress has been made towards achieving its implementation.

Additionally, the ongoing increase in demand for healthcare services – coupled with a challenging financial climate – has propelled the issue of large-scale transformation of services from important to imperative. This will require a reorientation of services away from traditional, paternalistic models of care to an approach focused on prevention, empowerment and pro – active management, with the underlying premise being that – over time – these models will be more efficient. This presents a challenge for commissioners and health care planners as the success of person centred care relies on improving integration across and between health and social care services, with the result that financial savings are realised by this approach are likely to be spread across these sectors.

### **The healthcare context**

The changing story of cancer is rapidly evolving, posing significant challenges to the healthcare sector.

With population ageing and survivorship rates increasing, there will likely be an increasing demand for healthcare services by people living with cancer.

This increase in population size is happening at the same time of the predicted budget cuts in the sector throughout the UK. NHS England predicted a £30bn shortfall in funds by 2020.<sup>13</sup> NHS Wales is predicted to face a funding gap of £2.5 billion by 2025/26.<sup>37</sup> Scotland and Northern Ireland are also struggling to cope with restricted budgets and funding cuts.

These issues highlight the need for a more efficient healthcare system that can cope with increasing pressure and demand. One of the possible solutions to this challenge is the development and implementation of Support Worker roles, which directly provide support as well as free up capacity of registered practitioners.

### **Specialist staff performing other duties**

In the context of a pressurised health system, with demand and complexity rising and a variable and uncertain workforce supply, it makes sense to consider how the existing workforce can be supported to be more productive.

CNSs highlight the lack of time and resources they have to dedicate to patient interaction and to perform interventions recognised as crucial for improved patient outcomes (such as completing a Macmillan holistic needs assessment and the associated tailored Care Plan).<sup>20</sup> But it's been estimated that around 20-30% of CNS time is used on administrative tasks and specialist skills are not being optimised.<sup>27</sup>

Skills for Care have also identified an element of over-qualification, or at least feeling over-qualified in the UK. In all the labour market, around 30% of workers consider themselves over-qualified for their current job. In clinical settings, this translates to clinicians with a high qualification carrying out tasks that could be done by staff with a lower qualification.<sup>3</sup>

Skills for Health also identified that around a quarter of the support workforce are qualified at level 4 or above – signalling that there is capacity to take on more complex activities. In a future scenario where more people will be accessing cancer services, it is crucial to make sure that skills in the current workforce are used efficiently.

Hence the need to develop a skill mix approach including the establishment of a Support Worker role that will support clinical staff, taking on some less complex tasks and allowing them to make best use of their expertise.

### **Support workforce development**

There are many types of “support” roles in the health and social care sector. Working closely with the clinical staff and under supervision, they can provide direct care to patients, enhancing current service provision.<sup>2</sup>

Skills for Health asked employers to identify potential improvements which might result from a structured implementation of support worker roles in the healthcare setting. These are:

- Improving patient safety and quality of care
- Making improvements to workforce and staff
- Improved processes and working practices
- Potential financial and productivity improvements<sup>2</sup>

All this suggests how, when adequately structured and implemented, support worker roles in clinical settings can lead to both improvements in quality of care and an optimisation of resources.

In Wales, the NHS will need to implement new strengthened training standards for healthcare support workers introducing a common set of standards for training and education, recognising the skills, knowledge and experience of individuals as they develop in their role.<sup>36</sup>

### **The economic case is strong**

The economic case for support workers to be used more widely in the health and social care sector is quite strong.<sup>2</sup>

Implementation of a wider support workforce can result in financial savings for both patients and hospitals. These result from fewer visits to hospitals and GPs. Patients save money on unnecessary travel and transport, while hospitals limit the number of interventions.<sup>22</sup>

Staff costs account for the largest part (63% in 2013/14) of NHS total expenditure.<sup>23</sup> Optimising and tailoring roles so that resources best used to meet the increasing needs and demands is therefore crucial for the long-term sustainability of the system. This is to ensure that services and the workforce delivering them work effectively, delivering high quality care.<sup>2</sup>

Evidence shows that implementing a wider support workforce helps make best use of existing resources, contributing to a more efficient service provision to meet increasing demands and challenges.<sup>2</sup>

Currently, clinical support roles at level 4 (like healthcare assistants and assistant practitioners) represent 17% of the workforce in the sector across the UK. Predictions suggest that increasing the number of support workers from 236,000 to 255,000, keeping the same number of AHPs and Nurses, could notionally save £100m a year in England only.<sup>2</sup>

### **There remain concerns around the support workforce**

Despite the advantages and potential improvements resulting from a structured implementation of support workforce, concerns around support workers with higher qualifications and responsibilities are very much alive. Most of these concerns revolve around a lack of clarity of the role.<sup>3</sup>

Because support workers carry out tasks traditionally associated with clinicians (particularly nurses), it is important to clearly define roles, responsibilities and accountabilities for the whole workforce.<sup>18</sup> To allow a certain degree of flexibility and autonomy, employers can develop specific procedures which clearly define the roles of healthcare assistants and assistant practitioners within their Trusts and Health Boards. This is aimed at avoiding confusion within Trusts and Health Boards about responsibilities of the different elements in the workforce.<sup>2</sup>

We are also mindful of the need to maintain a degree of flexibility with support worker roles, allowing employers to develop tailored descriptions of the roles. Responsibilities of the support workforce within each Trust and Health Board and the potential for development need to be clearly set up.<sup>3</sup>

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

Macmillan's response is to support a holistic, personalised approach that is well coordinated and integrates health and social care support, so that people with cancer have access to a mix of people that make up the cancer workforce. To ensure people with cancer receive one-to-one support, we need to build teams so that they can see the right person with the right skills and knowledge at the right time.

Macmillan is continuing to look at what the cancer care teams of the future must look like. They will need to be more flexible, working with people living with cancer to identify their concerns and support them in managing their own care.

Access to a CNS is strongly associated with a good patient experience. And whilst the number of people being assigned a CNS continues to rise, from 84% in 2010 to 89% in 2014 in England, this still means that around one in 10 people with cancer are denied the expert care and support that a specialist cancer nurse can provide. In some areas, this rises to more than one in five. And there is huge variation in how easy people find it to contact their CNS.

In 2012 Macmillan started piloting four Macmillan One-to-One Support roles across the UK. These pilots have been evaluated in 2015.

Macmillan One-to-One Support Workers perform a wide range of duties, both supporting people living with cancer and helping establish a skill mix approach.

## Cancer system change

### i) Models of aftercare

The National Cancer Survivorship Initiative (NCSI), which includes Macmillan, the Department of Health in England and NHS Improvement, has been working to develop new models of aftercare. According to these models, interventions should be measured and evaluated against three levels of care. The NCSI defines these levels as follows:

- **Supported Self Management** – where patients are given the information about self management support programmes or other types of available support, the signs and symptoms to look out for and who to contact if they notice any, what scheduled tests they may need such as annual mammograms, and how they get in touch with professionals if they have any concerns.
- **Shared Care** – where patients continue to have face to face, phone or email contact with professionals as part of continuing follow up.
- **Complex Case Management** – where patients are given intensive support to manage their cancer and/or other conditions.<sup>4</sup>

In its 2013 evaluation, NHS Improving Quality showed that modelling care around the new pathways helps deliver better quality outcomes.<sup>5</sup>

Macmillan also identified a collection of specific cancer recovery interventions that, when implemented correctly, can improve the outcomes of people living with and beyond cancer. These form the Macmillan **Recovery Package**, where supported self-management is key to the whole process.<sup>17</sup>

The **Macmillan Support Worker** role has been developed with the purpose of helping people affected by cancer with non-complex needs to manage their own care. This reflects the supported self-management principle set out by NCSI and Macmillan. Implementing the self-management principle allows people living with cancer to be more in control. They



*'My Macmillan One-to-One Support Worker has been able to provide advice, support and just someone to talk to. I can't praise her enough'.<sup>1</sup>*

**Cancer patient**

participate more with professionals in shaping their preferred model of care, as well as having the support of a qualified expert as appropriate throughout their journey.

## **ii) Redesigning the system**

Macmillan knows that individual needs of people with cancer are best met through interactions with a mixed workforce. The role of the Macmillan Support Worker is a step towards integrating the workforce in the health and social sector, so that people can benefit from interactions with a different range of professionals.

National policies and strategies for the healthcare sector identify the need to introduce changes to the current system. A more efficient workforce, with skills used in the best possible way, is a crucial step in this direction.

The Macmillan Support Worker role needs to be considered in this context. It enables improvement of the care pathway as a whole, in a more sustainable way. The role supports the Macmillan Recovery Package and helps the redesign of follow-up to best meet the needs of people with cancer.

## **Key features of the Macmillan One-to-One Support Worker role**

These features are also common to many other similar roles established outside of the National One-to-One pilot.

### **a) First point of contact**

One in 10 people are not assigned a CNS in England and there is considerable variation in how easy people find it contact their CNS.<sup>24</sup> Due to the difficulties in navigating the system, it is often hard for people with cancer to identify the best way to receive support. The creation of the Macmillan One-to-One Support Worker role aims to address this problem.

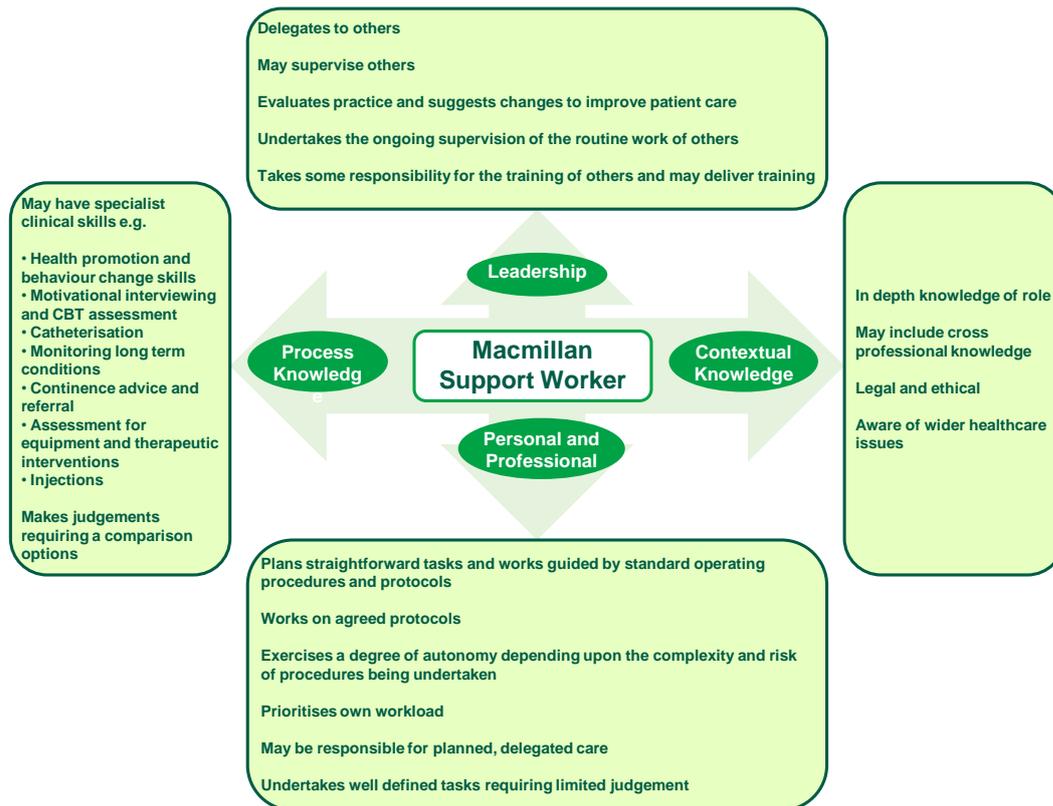
Macmillan One-to-One Support Workers provide the first point of contact to people after cancer treatment who can be supported to self manage. In some of the pilot sites, each cancer patient is referred to a specific Macmillan One-to-One Support Worker, who becomes the key contact throughout the cancer journey, both in- and post-treatment.<sup>9</sup>

Guided by the Macmillan One-to-One Support Worker, each individual identifies their needs at key transition points and is enabled to access services and support as appropriate. This is important not only because it helps identify and address needs of people sooner. It is also crucial in empowering people living with cancer, helping them understand and take charge of their care.

This role helps establish effective supported self-management for people with less complex needs. This is identified at a national level as a key factor to address for an optimisation of healthcare.<sup>4</sup>

### **b) Level 4 qualified interventions**

The overall structure of Macmillan One-to-One Support Worker role follows a similar framework to that defined for Assistant Practitioners (Level 4) in healthcare:



Unlike most of the support workforce, they are recruited at level 4 in the NHS Career Framework.<sup>14</sup> The majority of the support workforce is typically recruited at level 2 or 3, and carry out limited types of interventions, most of which involve limited direct support to patients.

The level 4 competency also means that, under the supervision of healthcare professionals, One-to-One Support Workers can directly interact with and support people with cancer, to shape their care.

### c) Work with clinicians

Some of the activities of the Macmillan One-to-One Support Workers have a direct impact on the work of clinical staff. The role has been developed to work alongside healthcare professionals, enabling the more specialist staff to use their skills where they are most useful.

The interventions that One-to-One Support Workers can undertake are varied. The flexibility of the role makes sure that each trust or Health Board that uses support workforce can tailor the job description to make it cover what is most needed.

Working alongside CNSs and other AHPs, Macmillan One-to-One Support Workers contribute to better management of clinical workforce and skills overall

*'The Macmillan One-to-One Support Worker has helped me enormously, I feel it is a better use of time to speak to the One-to-One Support Worker rather than the CNS who is very busy and has a clinical focus'.<sup>20</sup>*

**Cancer patient**

#### d) Support for people living with cancer

Activities that Macmillan One-to-One Support Workers carry out with people living with cancer are varied, in order to meet the specific individual needs. These might happen face-to-face or using other means of communication (such as phone or email).

Some of the key activities that Macmillan One-to-One Support Workers carry out are:

1. Facilitate **patient understanding** of the health and social care system, helping them to access the support available
2. Support people to contribute to the development of their own **care plan** to better suit their needs and preferences
3. Directly support people with **non-complex needs**, providing **emotional and practical** support and advice
4. **Signpost** people with more complex needs to the relevant healthcare professional

#### e) Improving access to the appropriate level of support

As Macmillan One-to-One Support Workers support people to work through their concerns and priorities for their lives, they are in the best place to facilitate the interaction of patients with other healthcare professionals.

By triaging requests and referring people only when relevant, clinicians can focus their time, skills and expertise on the most appropriate cases. This improves the overall quality of care provided.

At the same time, everyone with a cancer diagnosis can benefit from tailored, person-centred support. Complex cases are dealt with by specialist staff and non-complex cases by Macmillan One-to-One Support Workers.

## 3. What is the impact of Macmillan Support Workers?

The impact of level 4 support roles, like the Macmillan Support Worker, is very positive and backed by substantial evidence derived from the implementation and piloting of these kinds of positions. Most of the evidence below refers to the Support Worker role in the One-to-One Support pilot, but it is largely valid for level 4 Macmillan Support Workers in general.

A properly resourced and organised support workforce improves patient satisfaction and experience, as well as making the work of clinical staff less stressful by relieving them of unnecessary duties. Also, the whole system behind the health workforce becomes more sustainable.<sup>3</sup>

*'I am more confident and open about things, and it is reassuring to know I can talk to someone in a relaxed way.'*<sup>1</sup>

**Cancer patient**

## a) Impact on people living with cancer

### Better outcomes

Following the successful piloting of Macmillan One-to-One Support Workers in various Trusts, Macmillan evaluation collected feedback on the perceived quality of care of the people being supported.

People living with cancer rated the quality of support received in Macmillan One-to-One Support pilot by on average 9.3 out of 10, with other healthcare professionals rated 7.7.<sup>1</sup>

In the evaluation of the pilot services, 89% of respondents said they had no further support needs following the interaction with one of the Macmillan One-to-One Support roles.<sup>1</sup>

Reported impacts of Macmillan One-to-One Support Workers on people living with cancer are:

- reduced feelings of isolation and loneliness
- feeling understood and valued
- relief of worries and stress
- increased level of knowledge and information
- increased level of independence
- increased drive to proactively manage own care and life

Reported impacts of Macmillan One-to-One Support Workers on family members are:

- better placed to provide support
- improved understanding of symptoms and needs
- (for parents) increased confidence in telling children about diagnosis/terminal illness<sup>1</sup>

### Improved communication

People living with cancer found the Macmillan One-to-One Support service easy to contact and very simple to access.<sup>20</sup> Results from the pilot evaluation show that those who received support through the service particularly valued the ability to communicate and the thorough understanding of their needs that Macmillan One-to-One Support post-holders demonstrated.<sup>1</sup>

People with a cancer diagnosis also reported that one of the vital aspects of receiving support through Macmillan One-to-One Support Workers was having someone not family-related to talk to about emotional and psychological concerns. This is important as some people did not feel comfortable to disclose such personal information to family members and/or did not want to add any further burden on those who were already heavily involved in their care and support.<sup>1</sup>

People with cancer also valued having someone to talk to throughout their cancer journey as this helped them to feel less isolated. It also relieved them of worries and stress related to their condition.

Figure 4.4: Do you think you would have received appropriate care and support without the support of your Macmillan One-to-One Support worker? (N=128)

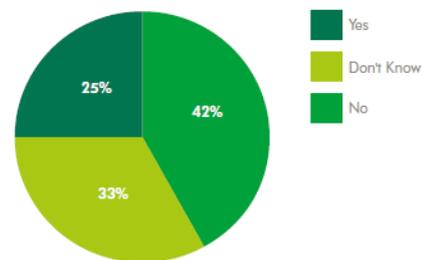
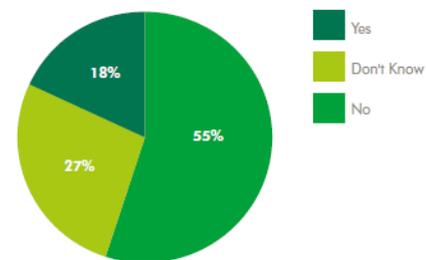


Figure 4.5: Do you think you would have received appropriate support to deal with the consequences of your cancer/treatment if you had not had access to a Macmillan One-to-One Support worker (N=163)



### **Better understanding of the system**

Besides providing face-to-face support to people with cancer (in both survivorship and end of life) Macmillan One-to-One Support Workers have a key role in helping people understand and navigate the healthcare system easily and quickly. A good part of their interventions are related to signposting people to the right specialist or service.<sup>1</sup> This is particularly relevant considering that most people find the current healthcare system too confusing and professionals might fail to recognise issues and provide adequate support.

After interaction with a Macmillan One-to-One Support Worker, people living with cancer reported they felt more empowered. Thanks to the expertise of the Macmillan One-to-One Support Workers, they have an increased understanding of the healthcare system and are more informed about how the sector works.

Also, by discussing care options and co producing some of their care plan with the Macmillan One-to-One Support Worker, people felt more in control. They understood the next steps of their treatment and recovery, as well as being in the position of making informed decisions.

## **b) Impact on the healthcare system**

### **Better outcomes for the system**

Macmillan One-to-One Support Workers play a vital role in ensuring people living with cancer are at the centre of their post-treatment care. The benefits of an effective supported self-management pathway are multiple, ranging from improved patient experience to easing pressure on the healthcare system.<sup>5</sup> People with less severe needs can manage their own healthcare with the help of a support workforce, while clinical staff can concentrate on those with more complex needs.

The evaluation of the pilot of the Macmillan One-to-One Support Worker role shows that early signs of improvement in the healthcare system are already visible. Working closely with CNSs and other AHPs, Macmillan One-to-One Support Workers undertake a variety of tasks, which allows clinical staff to focus their skills and time where they are most impactful. Also, they offer a much needed first point of contact for people who can go to the Macmillan One-to-One Support Workers to receive initial support and/or be signposted to the relevant health professional or service.<sup>1</sup>

When asked about the pilot of the service, CNSs at UCLH in London emphasised the added value of Macmillan One-to-One Support Workers to both their own workload and overall patient care. They also noted the need to develop an infrastructure to properly sustain the support workforce, in order to get the best out of the role.<sup>20</sup>



*The Macmillan One-to-One Support Worker role has made a huge improvement to the quality of our service in the two years it has been running. It has enabled us to implement important initiatives such as HNA and Information Prescriptions, which would have otherwise been impossible to get off the ground.<sup>20</sup>*

**Cancer Clinical Nurse Specialist**

The Macmillan One-to-One Support pilot demonstrates that, when correctly developed, the support workforce can provide additional help that goes beyond basic administrative and clinical aspects:

- Support workers can enhance patient experience, supporting customers face-to-face and improving quality of care
- Higher-level (level 4) support workers can work with lower supervision from professional clinical staff
- Support workers also have a variety of skills that can be applied to different tasks
- Support workers can be the first point of contact for people, helping them navigate the system and coordinate their care plan with relevant parties (eg communities, hospitals, clinical staff, etc.)<sup>3</sup>

### Improved optimisation of system resources

The evaluation of Macmillan One-to-One Support Worker roles at UCLH in London also shows how most of the interventions carried out in the two-year pilot were outpatient focussed, and administrative activities were limited to cases where no administrative support was available for CNSs.<sup>20</sup>

The audit of the Macmillan One-to-One Support service in Forth Valley in Scotland found that the greatest improvement resulting from the pilot of the service is the structured introduction of Holistic Needs Assessments, Concerns Checklists and Care Plans. The support workers were praised for setting up major improvements in patient care.<sup>21</sup>

An audit undertaken by the Calderdale service after establishing a care co-ordinator in head and neck cancer showed that

- 144/154 (94%) reviews would have needed to have been completed by CNS if Coordinator had not done so.
- During 4 weeks this saved CNS an estimated 10 days.<sup>8</sup>

### The cost of funding a typical Macmillan One-to-One Support Worker<sup>16</sup>

<b>1 Hour</b>	£15
<b>1 Day</b>	£105
<b>1 Week</b>	£524
<b>1 Month</b>	£2,272
<b>1 Year</b>	£27,267

\*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.

## CONCLUSION

Macmillan Support Workers can be the first point of contact for people living with cancer. They provide emotional and practical support, also helping people to navigate the healthcare

system more confidently and self-manage. With the support of Macmillan Support Workers, people living with cancer feel empowered and take control of their care.

Working closely with CNSs and other AHPs, Macmillan Support Workers also help to achieve a more efficient use of workforce in the healthcare sector. They undertake lower level interventions, allowing registered clinical staff to use their skills in helping people with cancer with more complex needs.

Macmillan continues to fund and support Support 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.

### Case Study 1:

#### Cancer Care Co-ordinator, Calderdale and Huddersfield<sup>8</sup>

The role of the Cancer Care Co-ordinator in Calderdale and Huddersfield NHS Foundation Trust is similar to the Support Worker role piloted in One-to-One Support.

Working with the Macmillan Head and Neck team, the Cancer Care Co-ordinator is the first point of contact for patients and families, undertaking care reviews throughout the pathway. Interactions are done either managing calls, email and fax or giving face-to-face information. When appropriate, a review by the Cancer Care Co-ordinator can trigger a clinical intervention.

Between January and May 2015, the Cancer Care Co-ordinator role has been audited and the review has identified how the role is having a direct and positive impact on the overall system.

The main benefit of the role is that its interventions save time and resources which would have been otherwise used. Support given to CNSs is key, in this sense. The audit found that a CNS would have used an extra 201.3 hours over the period of the audit (January to May 2015) if the reviews had not been carried out and interventions had not been put in place by the Cancer Care Co-ordinator. CNSs have not been the only ones benefiting from the work of the Cancer Care Co-ordinator, with professionals such as SALTs (speech and language therapists), dieticians, district nurses, GPs and services such as A&E also being able to improve the management of their workload.

#### Breakdown of 154 interventions over 4 weeks:

- **Level 1 Interventions:** Simple problem solving - 91/154 (59%)
- **Level 2 Interventions:** Single Patient Contact to resolve a specific clinical / non clinical problem - 50/154 (32%)
- **Level 3 Interventions:** Short term involvement for multiple problems - 12/154 (8%)
- **Level 4 Interventions:** Interventions for patients with complex problems - 1/154 (1%)

144/154 (94%) of interventions would have needed to have been completed by a CNS if a Cancer Care Coordinator had not done so. During the 4 weeks the CNSs saved an estimated 10 days of working time.

## Case Study 2:

### The Link Worker in Improving the Cancer Journey (ICJ) programme<sup>9</sup>

ICJ is a partnership between Glasgow City Council, Macmillan Cancer Support, Greater Glasgow & Clyde NHS, Glasgow Life, Cordia and The Wheatley Group. It is funded by Macmillan and its aim is to create a high quality cancer care service for people affected by cancer in the Glasgow area, based on Holistic Needs Assessment (HNA) and supported self-management.

ICJ's aspiration is aligned with the national strategic vision promoted by the Scottish Government in different publications, like the *2020 Vision for Health and Social Care*<sup>10</sup> and the *National Health and Wellbeing Outcomes Framework*.<sup>11</sup> These are focused on a patient-centred model of care, with a system in place that supports and empowers patients to be active part of their care.

Part of the success of this model is due to the support service carried out by Link Workers. This role is similar to the One-to-One Support Worker role, piloted by Macmillan. After completing the HNA (assessing the main concerns) and the Distress Thermometer (assessing the level of stress), cancer patients are assigned to a Link Worker, with whom they discuss the results of the assessments and devise a Care Plan. The Care Plan is then passed on to the relevant healthcare professional.

With this model of supported self-management, patients are empowered and feel more in control of their care. Also, the Link Worker is their first point of contact throughout their journey. Patients can discuss their care plan with their Link Worker, as well as receiving support about their concerns and, when appropriate, being signposted to specific professionals and/or services.

An audit of the service conducted confirmed that ICJ is achieving excellent outcomes, based on HNA assessment and supported self-management. These include

- 5,826 concerns identified using the HNA tool.
- 2,555 onward referrals made to more than 171 support services.
- 97% of respondents rating the Service as excellent.
- Average 50% reduction in patient reported stress levels following their first HNA.
- £701,000 identified in Financial Gains for cancer patients.
- 70% of respondents saying that the ICJ Service was directly responsible for stress reduction and increased overall health and wellbeing.
- 61% patients helped to self-manage their concerns with 37% of people no longer needing the dedicated support of a Link Worker.

# REFERENCES

- 1 Macmillan Cancer Support. *Evaluation of Phase 1 of the One-to-One Support Implementation*. 2015.
- 2 Skills for Health. *Working Paper Series: The Healthcare Support Workforce*. 2015.
- 3 Skills for Health. *Working Paper 2: How we can act now to create a high quality support workforce in the UK's health sector?*. 2015.
- 4 National Cancer Survivorship Initiative (NCSI). *Stratification Process*. 2013.
- 5 NHS Improving Quality. *Stratified Cancer Pathways: redesigning services for those living with or beyond cancer*. 2013.
- 6 Macmillan Cancer Support. *The Reach of Macmillan's Services factsheet*. 2015.
- 7 Department of Health. *Improving Outcomes: a Strategy for Cancer*. 2014
- 8 NHS Calderdale and Huddersfield. *Cancer Care Audit*. 2015.
- 9 Improving the Cancer Journey. *Making a Difference to People's Lives Through Effective Integration of Health & Social Care*. 2015.
- 10 The Scottish Government. *2020 Vision*. 2015.
- 11 The Scottish Government. *National Health and Wellbeing Outcomes*. 2015.
- 12 Welsh Government. *Together For Health – Cancer Delivery Plan: Our Vision*. 2012.
- 13 NHS England. *Five Year Forward View*. 2014.
- 14 NHS Career Framework. 2010.
- 15 The Scottish Government. *Scottish Cancer Patient Experience Survey*.  
<http://www.gov.scot/Topics/Statistics/Browse/Health/cancersurvey>
- 16 Macmillan Cancer Support. *The Cost of Macmillan's Services factsheet*. 2015.
- 17 Macmillan Cancer Support. *The Recovery Package*. 2013.
- 18 King's College London National Nursing Research Unit. *Moving Forward With Healthcare Support Workforce Regulation*. 2010.
- 19 Macmillan Cancer Support. *Hidden at Home: the social care needs of people with cancer*. 2015.
- 20 NHS University College London Hospitals. *Report on the Introduction & Evaluation of the Macmillan Cancer Support Worker Role at UCLH*. 2014.
- 21 NHS Forth Valley. *Report Re Macmillan One to One Pilot Project Phase 1*. 2015.
- 22 Health Economics Consulting. *Evaluation of the Transforming Cancer Care in the community (TCCC) programme: an economic and quality assessment of new models of care in the Anglia Cancer Network*. 2015.
- 23 The Health Foundation. *Hospital finances and productivity: in a critical condition?* 2015.
- 24 Quality Health. *Cancer Patient Experience Survey*. 2014.
- 25 The Health Foundation. *Person Centred Care: from ideas to action*. 2014.
- 26 Department of Health. *Improving Outcomes: a Strategy for Cancer*. 2011.
- 27 Leary, A. and Oliver, S. Clinical nurse specialists: adding value to care. *Royal College of Nursing*. 2010.
- 28 Macmillan Cancer Support. Estimate for 2015 based on extrapolation of data in: Maddams J et al. Projections of cancer prevalence in the United Kingdom, 2010-2040. *British Journal of Cancer*. 2012. (Projections scenario 1)
- 29 Cancer Research UK. *Cancer Survival Statistics*. 2014.
- 30 Macmillan Cancer Support estimates. 2014. Incidence predictions are based on the assumption that age specific all cancer incidence rates remain constant at 2012 rates. Predictions based on applying the UK 2012 incidence rates for 5 year age groups to 2012-based population projections from the Office for National Statistics. Latest incidence figures for each nation taken from Office of National Statistics, ISD Scotland, Welsh Cancer Intelligence and Surveillance Unit and from personal communication with the Northern Ireland Cancer Registry.
- 31 Health and Social Care Information Centre (HSCIC). *Hospital Episode Statistics*. 2014.
- 32 National Audit Office. *Tackling Cancer: Improving the Patient Journey*. 2005.
- 33 Picker Institute. *Cancer Follow Up Care*. 2009

- 34 Macmillan Cancer Support. *Living After Diagnosis: median cancer survival times*. 2011.
- 35 Quality Health. *Northern Ireland Cancer Patient Experience Survey*. 2015.
36. NHS Wales. *Developing Excellence in Healthcare*. 2015.
37. The Nuffield Trust. *A decade of austerity in Wales? The funding pressures facing the NHS in Wales to 2025/26*. 2014.
38. Quality Health. *Wales Cancer Patient Experience Survey*. 2014.