

**WE ARE
MACMILLAN.
CANCER SUPPORT**

**THE SOCIAL
CARE NEEDS**

**OF PEOPLE
AFFECTED
BY CANCER**

Research insights

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Research insights

Objectives

- to establish what is currently known (and therefore unknown) about social care for people affected by cancer
- to inform the development of the second version of an invitation to tender (ITT) for externally-commissioned research into social care for people affected by cancer.

Scope and approach

The approach was one of desk-based research using the following sources:

- internet searches
- Pub Med
- Web of knowledge.

We also carried out meetings with key internal stakeholders.

Excluded from scope

- health and social care integration
- social care for children.

Definitions

- **Social work:** Social work is a registered profession, providing advocacy for people affected by cancer to advise and negotiate access to relevant psychological, emotional, practical, financial and personal support. Social work can include assessing needs, arranging care packages, planning hospital discharges, and liaising with other service providers. Social work is provided in various settings including hospitals, hospices and the person's home.
- **Social care:** Any form of support by anyone competent to assist someone with their care needs. These include personal and practical support, information and signposting, housing, employment, finances and issues relating to social isolation.
- **Carers:** A carer is someone who looks after a person with cancer who could not manage without this help. The carer isn't paid for providing this support.
- **People affected by cancer:** People affected by cancer – this includes people living with and beyond a cancer diagnosis and carers of people with cancer.

Executive summary

- The needs of many people affected by cancer are not being met, resulting in financial hardship, emotional distress and being unable to get on with daily life. Significant clusters of unmet needs concern the management of daily life, emotions, and changing social identity. This suggests cancer services are less responsive to the non-clinical aspects of the cancer experience.
- The social care needs of people affected by cancer will vary greatly from person to person. They will be influenced by the cancer journey stage, demographic and socio-economic status, and the level of caring support provided.
- People affected by cancer have practical, emotional, financial and information needs. Practical needs encompass all the things essential for daily living such as help with running the household (cooking, cleaning, support with looking after children and pets), personal hygiene and attending appointments. Emotional support needs can vary and may simply involve having someone to talk to. People affected by cancer often notice a decrease in income and require advice on the financial support available to them. Throughout the cancer journey information is important, whether this is signposting to support or details about what to expect.
- Cancer carers have similar needs to those living with cancer but also unique needs such as bereavement support.
- A consensus exists among the NHS, local authorities and people affected by cancer as to what constitutes social care needs – this does not mean these needs are being met.
- A great deal of social care support is provided informally by friends and family, particularly for those whose needs are not viewed as critical or substantial. As such, they receive no support from local authorities.
- Current estimates are that 1.1 million people provide caring support to someone with cancer and Carers UK estimates that *all* carers save the tax payer approximately £119 billion per year (Carers UK, 2001) – equivalent to £2.3 billion per week. The number of people living with or beyond cancer is expected to double by 2030 to four million. The number of people providing informal support is growing.

- People affected by cancer are not always referred to appropriate services and do not always have their needs identified. Many people do not know what services are available. A lack of integration and limited resources mean people are missing out on vital support.
- State funding for social care is changing, but people affected by cancer continue to pay for a high proportion of their own care.
- Macmillan offers a variety of social care support including Macmillan professionals, information, emotional and financial support, and support for carers, friends and family.

The majority of the social care needs of people affected by cancer are applicable to both carers and people living with or beyond cancer

The *Macmillan Social Care for Cancer* report identifies that social care needs vary considerably throughout the cancer journey and from person to person. People affected by cancer have a wide range of emotional, practical, financial and information needs.¹

Social care needs for people with cancer vary according to age, gender, socio-economic status and stage of the cancer journey, whether that is diagnosis, treatment, follow up, remission, relapse or end of life. People with cancer have specific and complex social care needs. These can be due to the length and nature of their treatment, impact of treatment on mobility and ability to perform daily tasks. They also include the emotional impact of diagnosis and treatment, and carer support needs.²

Identified emotional support needs can range from talking to someone on an informal basis to receiving structured support from a qualified professional.³

People with cancer and their carers report that telling their family and friends was particularly hard. Few say that they were given any information, advice and support about how to handle this.

A total of 58% of people affected by cancer feel that their emotional needs are not looked after as much as their physical needs. While 59% of carers and 51% of people living with cancer think that providing services to help with the emotional aspects of cancer is important. Both groups prioritised this above medical and practical aspects.^{4,5}

Practical support needs tends to focus on day-to-day tasks including shopping, cleaning, gardening, helping with childcare, offering lifts, showering, collecting prescriptions and assisting with the stairs.

Four out of ten people living with cancer (41%) say that the physical effects of their cancer or treatment are difficult to cope with. This can include tiredness and exhaustion.⁴

Failing to meet practical needs can also have a knock-on effect on people's emotional and physical wellbeing.

As many as 91% of households suffer a loss of income and/or increased costs as a direct result of cancer.⁶ People affected by cancer also want advice and signposting about work and employment issues.⁷

People affected by cancer have emotional, practical, information and financial needs.

The need for emotional support ranges from wanting someone to talk to, to discussing difficult issues such as end of life care

Macmillan's *It's No Life* is explicit about the need for healthcare professionals to move beyond an acute clinical model of care and recognise the long-term emotional and psychological side effects of cancer.⁸

The Macmillan report *Worried sick, the emotional impact of cancer* identifies that emotional needs and support are key. It shows 45% of people with cancer say that the emotional aspects are the most difficult to cope with. Further to this, 49% want or need information, advice or support about the emotional aspects of a cancer diagnosis but 41% of these people are unable to get this help.⁴

The need for support also extends to family members. Participants in one survey of cancer survivors in England report members of their family also needed some emotional support to help come to terms with the condition of their loved one. They also wanted practical advice concerning the support which could be provided to them.⁹

More than two thirds of carers of people living with cancer experience anxiety as a result of their cancer diagnosis. Of those, more than 85% do not receive information, advice, treatment or support to specifically help with their concerns.²

Emotional needs can take many forms including locating sources of hope for the future (cited by 70% of respondents in one study)¹⁰. They can also include recognising fears around reoccurrence and genetic links to children, and support for those who feel depressed or lonely.⁹

People also want support to understand changing self-identity, change in body and self-image.¹⁰

Research into end of life care shows that people want to be treated as individuals, not primarily as patients or older people. They want to be treated with respect and involved in decisions relating to their treatment and care. They want health and social care professionals to talk to each other so that care may be planned appropriately. They want decisions relating to treatment and care at the end of life to be equitable. They don't want them based on postcode, ability to pay, or the ability of the individual or their family to articulate need.¹¹ This is strongly linked to the fact that two in three people (65%) living with cancer in England who died in hospital in 2011 wanted to die at home.¹²

Information needs are key throughout the cancer journey for people affected by cancer

A study examining the needs of people living with cancer and cancer carers shows that 80% of respondents rate information needs as 'very important' or 'important'. This includes obtaining full information about what to expect from the disease and its treatment, treatment timetables and schedules, services, and additional sources of information.¹⁰

Information needs can include wanting support on how to tell people about a cancer diagnosis, how treatment will affect a person with cancer and what to expect when treatment finishes. They may also involve wanting to know what support is available emotionally, practically and financially.

The Macmillan *Social Care for Cancer* report highlights that being referred for tests and waiting for results was a particularly anxious time, when little or no information, advice and support was perceived as available. The same is true after treatment finishes when people living with cancer feel advice and support diminishes.

People affected by cancer will need varying degrees of financial support due to loss of income and increased outgoings

People living with cancer say they can find it hard or impossible to work during their treatment and beyond. The consequence of this means many of them have financial needs, which can be exacerbated by unexpected costs such as hospital car parking fees. This is also particularly impactful for people affected by cancer who are self employed. The level of financial support needed can vary greatly, from help with travel and parking fees to help with mortgage payments. Long-term financial support, such as state benefits, can be needed if a return to work is not possible. Or people may have access to other financial services, for example life assurance, pensions and travel insurance.¹³

People living with cancer can also experience increased costs such as hospital parking, larger heating bills, or the need to buy new clothes, bedding or different types of food.¹³

Many people affected by cancer who are returning to work also feel there is a lack of assistance to facilitate this.⁹

People living with or beyond cancer can describe the various financial difficulties they face, particularly worries about declining income and the process of returning to work. These financial concerns often compound ongoing physical and psychological problems already impacting negatively on their quality of life.⁹

Cancer carers can also experience increased outgoings as highlighted on page 13 of this report.

Practical support can be required in the short and long term and will need to be flexible.
Practical needs reflect people living their daily lives

The frequency of treatment (spread over days, weeks or months) can limit what people can practically do. Surgery itself can also limit people's physical strength temporarily or permanently. As a result, people living with or beyond cancer require support that is flexible. People living with or beyond cancer say they can find it difficult to run a household and carry out activities such as shopping, cooking and cleaning. They can also have mobility issues such as difficulty climbing and descending stairs. The practical support required may also include assistance with getting to hospital appointments or maintaining person hygiene.¹⁴

Practical support encompasses all the tasks and aspects of everyday life.

In addition to the effects of cancer and/or treatment, nearly half of all people living with cancer have at least one other long-term condition. Nearly a quarter have at least two.¹

The social care needs of carers broadly reflect the needs of people living with or beyond cancer. Cancer carers have some unique needs such as respite care or bereavement support

Partners and those close to people living with cancer can also experience psychological distress or develop affective disorders. Carers are likely to become more distressed and develop mental health issues as the illness advances and treatment becomes palliative. As many as 43% of carers reported at least one significant unmet need, for example managing daily life, emotions and social identity.³

Carers have emotional needs and may need support, with 46% saying caring impacts on their own mental health and emotional wellbeing, including increasing feelings of stress, anxiety, depression and isolation.³ Carers also want someone they can talk to.

Depending on the extent of their carer duties, carers may also find it hard to go to work. For some, this can result in disputes with employers about access to flexible working or extended leave. It can also impact on income with the expense caused by trips to hospital or reduced working hours.² Cancer carers can also need respite breaks.²

Information is important to many people affected by cancer.¹⁵ This can include information about the general support available.

Carers want to know how to provide more effective care themselves, for example how to encourage eating and help with physical movement. Carers may also need bereavement support.¹⁵

Carers may also need help with practical support such as childcare duties and running their own homes when they don't live with the person they're caring for.¹⁶

As with people living with or beyond cancer, carers' needs can vary greatly depending on stage of journey, age, gender, and socio-economic status.

There is also a growing market of parents who combine looking after young children with caring for older or loved ones who are disabled. This is sometimes called 'sandwich caring'. This dual role sometimes comes at a cost, and carers may suffer ill health, face difficulties with accessing or staying in the labour market, or experience financial hardship. A total of 45% of these carers look after someone with a long-term condition such as cancer.¹⁷

The NHS highlights that medical needs are the most important but signposts a variety of other assistance available elsewhere. Reports from the Care Quality Commission outline the best practice in meeting needs, including the importance of individuality and emotional support

The NHS viewpoint is that medical needs are potentially the most important needs for a person with cancer. It also advises that a variety of other assistance is available. The list below shows social care needs and the support available as signposted by the NHS. These services are primarily delivered by local government (Health and Social Care Trusts in NI) (providing set criteria is met):

- Care attendants and social services can help with housework, washing and dressing or provide company so that a carer can take a break (respite care).
- Local councils can provide meals at home.
- Financial support is available in the form of benefits.
- Occupational therapists can arrange equipment or home adaptations to make life easier – this can include adding handrails or installing a shower downstairs.
- The charity and voluntary sector, including organisations such as Macmillan, can provide support.

- Information from Care Quality Commission inspectors shows services that maintain people's dignity and treat them with respect have a number of things in common. They recognise the individuality of each person in their care and help them to retain their sense of identity and self-worth. They take time to listen to what people say. They are alert to people's emotional needs as much as their physical needs. They give them more control over their care and the environment around them.¹⁸

The NHS signposts Macmillan as a key provider of additional support

The key findings below show people affected by cancer have a variety of needs which vary from person to person

- The social care needs of people affected by cancer vary throughout their cancer journey, by cancer type and by demographic.
- The social care needs of people affected by cancer can be grouped into broad categories: practical, emotional, information and financial.
- The practical needs of people affected by cancer concern supporting them in living their daily lives.
- The need for information is strong throughout the cancer journey.
- Emotional support is important for every person affected by cancer.
- People affected by cancer may require financial support due to decreased income and increased outgoings.
- Many similarities exist between the needs of carers and people living with or beyond cancer.

The table below highlights a strong consensus between the NHS, local authorities or Health and Social Care Trusts, people affected by cancer and Macmillan about the social care needs of people affected by cancer. The majority agree about the social care needs of people affected by cancer.

	Practical needs	Information needs	Emotional support	Financial aid or advice
NHS and local authorities/Health and Social Care Trusts	✓	✓	✓	✓
Person living with or beyond cancer	✓	✓	✓	✓
Carers	✓	✓	✓	✓
Macmillan	✓	✓	✓	✓

A good consensus will not always equate with an adequate meeting of needs

The needs of people affected by cancer are met by a variety of sources, with the majority met informally or through support offered by Macmillan

The NHS, local authorities/councils and the Department of Work and Pensions

People affected by cancer can be referred to a local authority or Health and Social Care Trusts through various means including a self-referral and a referral from a carer, friend, family member or health professional. Once the local authority is aware that the person may have needs it has a duty to carry out an assessment.

Page 13 outlines the type of support available to people living with cancer. However this can take time. Local authority performance indicators state that an assessment should be performed within 28 days, with services in place after a further 28 days.

Carers are also eligible for a local authority assessment of needs and the support to meet them. Support for carers is not well utilised. Only one in 20 carers receives a carer's allowance or has had a carer's assessment.³

Financial support for people living with cancer is not well utilised. 36% of terminally ill people living with cancer die without receiving Disability Living Allowance or Attendance Allowance – key benefits to which they are automatically entitled. The reasons for low take-up include people not knowing

that they are eligible, the perceived stigma of claiming state benefits and the confusing claiming process.

Macmillan

The majority of cancer carers (72%) can name a Macmillan support service for carers, and 35% say they have used at least one of these. This is equal to 25% of all the cancer carers interviewed. The most commonly used services are the most widely known: Macmillan nurses, and information or advice through the website. Both are used by 13% of carers who know of a Macmillan service.³

Almost three in four carers can name a service or activity they think Macmillan Cancer Support offers to people who care for someone with cancer. Support from a Macmillan nurse is the most well known (39%). Three in 10 mention information and advice through the website and one in five know Macmillan offers carers emotional support (22%) or gives information through a telephone helpline (19%).³

In 2012, Macmillan reached 1.9 million people with a cancer diagnosis and 600,000 carers of people with cancer.¹

Other charities, including Scope, Mencap and Alzheimer's Society, also provide support.

Carers

More than 1.1 million people provide caring support to someone with cancer. These carers represent significant social care and NHS cost savings by reducing bed days for people living with cancer and reducing demand for social care services.³

A study of cancer carers found that many provide a wide range of practical and emotional support for people with cancer. This includes shopping and helping round the house, talking to professionals on their behalf, and providing transport and emotional support.³

Additionally, carers can often be reluctant to ask for short or long-term respite care as they may see this as letting down the person they care for. Again, this represents a significant cost saving to the NHS and local authorities or Health and Social Care trusts.

Friends and family

Many people with low to moderate social care needs fall outside of the social care system and rely on friends and family to provide the emotional and practical support they need. Family and friends often shoulder many of the practical support needs of people with cancer. This is also true for carers with the most frequent provider of support to carers informal, via family members (44%) or friends (28%).²

Often, unmet needs exist for both people living with cancer and their carers, across the cancer pathway. The impact of not meeting needs including financial hardship, emotional distress and not being able to get on with daily life.

Many people affected by cancer have unmet financial needs and are pushed into poverty as a direct result.⁶

- As mentioned previously, many people affected by cancer receive no financial support. The impact of this can be vast leading to two thirds of carers spending their own income or savings on paying for care, with 65% living in fuel poverty. In 2008, more than half of carers cut back spending on food or heating due to financial difficulties.
- About one in five of all carers give up work to care in 2006, and carers lost more than £11,000 in annual income on average in earnings due to giving up work, reducing hours or reducing responsibilities at work. Almost three quarters of carers are worse off financially since they became a carer and 54% have debts as a result of caring. In a 2008 survey of carers, nine out of 10 said that their finances were worse than 12 months ago, and that they expected their financial situation to get worse in the next year.
- Many long-term carers have to work part-time, miss out on promotions or give up work altogether to care.
- The Macmillan *More than a million* report highlights that 9% of people affected by cancer get no financial advice or information with a further 8% getting no financial help.³

Unmet information needs exist throughout the journey. People affected by cancer experience both a lack of information (on reoccurrence and the support available), as well as information not being provided in a understandable way.

- People affected by cancer cite specific information needs that are not met as including a lack of information on diet, treatment and aftercare.⁹
- Information needs such as lifestyle changes for the individual and their family, information about symptoms and reoccurrence, and genetic information were some of the least met but still wanted needs.¹⁹
- More than half of carers of people living with cancer are unable to get information, advice or support about the services available to support them.
- In one study the need for 'help to manage my concerns about the cancer coming back' is the most frequently reported unmet need. Other unmet needs that rank in the survey's top 10 include 'I need help to reduce stress in my life' and 'I need information provided in a way that I can understand'.²⁰
- Carers often want to be with the person living with cancer in medical settings, and to receive information about treatments and care. However, carers often experience uncertainty about if, how and when they would be 'allowed' to participate in medical encounters, for example, being present during doctor-patient consultations and asking questions.¹⁵

Lack of emotional support means people affected by cancer may have no one to talk to and can experience anxiety and depression

- The Macmillan *More than a million* report shows that 10% of people living with cancer do not have someone they can talk to.³
- More than two thirds of carers experience anxiety as a result of the cancer diagnosis. However more than eight out of 10 do not receive information, advice, treatment or support to specifically help with this.³
- More than four in ten (45%) people living with or beyond cancer say the emotional aspects of cancer are more difficult to cope with than the physical effects.²
- Evidence from NICE shows that around the time of a cancer diagnosis, approximately 50% of people living with cancer experience levels of anxiety and depression severe enough to adversely affect their quality of life. About 25% continue to be affected during the following six months. Among those who experience recurrence of cancer, the prevalence of anxiety and depression rises to 50% and remains at this level throughout the course of advanced illness. In the year following diagnosis, one in 10 people living with cancer will experience symptoms severe enough to warrant intervention by specialist psychological/psychiatric services. Such symptoms can also be seen in 10–15% of people living with cancer who are in the advanced stage.²¹
- Feelings of anxiety and stress, and emotional impacts increase when caring for someone with cancer. Research shows that 38% of cancer carers spend more than 30 hours caring each week. It also shows that more than half of cancer carers feel anxious at least some of the time – more than any other type of carer.
- A quarter of carers say that caring for a person living with or beyond cancer means they do not spend as much time with friends and family.

Failing to meet practical support needs can mean people affected by cancer cannot undertake activities essential to daily life

- The Health Survey for England Social Care Module defines an unmet need as when a person has at least some difficulty with an activity and may need help and did not receive any help.²⁰ Using this definition, levels of unmet need were higher in women than men for those aged 65 and over, still living in private accommodation. Of women 31% and men 21% had experienced an unmet need with at least one Activity of Daily Living. While 17% and 14% respectively had an unmet need with at least one instrumental Activity of Daily Living.
- The activity with the highest levels of unmet need – 15% for men and 24% for women – was getting up and down stairs. It is true that the activity is not specific to people living with or beyond cancer. However, it can be hypothesised that a similar (if not higher) proportion of people living with or beyond cancer have an equal number of unmet needs.
- Unmet needs can include practical activities such as car parking near treatment centres alongside help with household chores and transportation, or concerns about the future.²
- One in eight carers say caring for a person living with or beyond cancer causes them physical health problems.

Unmet needs tend to focus on the management of daily life (practically and emotionally) with some people affected by cancer at greater risk of having unmet needs. Unmet needs can also lead to unnecessary hospital admissions

The types of significant unmet need among people affected by cancer cluster around aspects of managing daily life, emotions and changing social identity due to a diagnosis, rather than more clinical experiences and needs. This suggests cancer services are less responsive to the non-clinical aspects of the cancer experience than they are the clinical ones. This may cause significant difficulty for people living with cancer in particular circumstances.

Unmet needs tend to be in the practical, self-identity and emotional categories. These include: assistance with financial matters and welfare claims; advice about food and diet; help with housework; help in dealing with the unpredictability of the future and sad feelings; and help with sexual needs.

The Health Survey for England found that people affected by cancer with the following characteristics are at greatest risk of having unmet needs:

- people living with cancer including: younger people; those with a long-standing illness or disability; those who are socio-economically disadvantaged; those without a religious faith; those who have difficulty in talking freely to a carer

about their cancer; those whose social activities have been disrupted by cancer; and those with financial difficulties

- carers of people with cancer including: those who are not the partner or spouse of the patient; those who have existing caring responsibilities; those with only a few people to call on for help; those in poor health themselves; and those caring for someone in the palliative-care only phase.

We have found that carers had considerably more unmet psychosocial needs than people living with cancer.¹⁵

A total of 47% of cancer carers feel that their needs are not met or they are not receiving useful support. As many as 18% of carers want advice or training on how to provide care, while 9% want information on the general support available and a further 9% someone they can talk to.³

Research by Carers UK also shows that more than two million people in the UK have left jobs to care for loved ones with a disability, or who are sick or older. As many as 22% say they have seen their work affected

by caring responsibilities. While 4% say they gave up work and 6% cut their hours to care for an older or ill relative or one with a disability.²²

Nearly one third of hospital beds are taken by people who might not have needed them if their care had been better managed. More than 10% of beds are occupied by people with a condition that should not require emergency hospitalisation – conditions which, if well managed, are treatable in the community. A further 6% of beds are occupied by people who have been readmitted as an emergency within a week of being discharged.²³ Although this is not specific to people living with cancer, it highlights the severity of failing to meet needs.

There are several key reasons why the needs of people affected by cancer are not being met

- People affected by cancer are not being referred to services due to their medical needs being viewed as more important.
- They are given inadequate information on support.
- There are limited resources available from local authorities.
- Services are not integrated.
- There is a lack of identification as a carer.

People affected by cancer are not identified as having needs, not signposted or referred to the appropriate services, or unaware of the help and support available

The social care needs of people affected by cancer are inadequately identified and people are not signposted to appropriate support

- Traditionally, people with cancer tend to enter the system through the health system rather than the social care system. This can lead to their carers missing out on needs assessments and services, as the health service has no legal duty to identify and signpost carers to sources of support. Local authorities/ Health and Social Care Trusts have also expressed concern that their staff may not understand the needs of people affected by cancer enough to assess them effectively. They feel that training is required to understand the needs of people with different long-term conditions such as cancer. This applies to all types of needs including providing emotional support. Local authority commissioners tend to view emotional support as the responsibility of health care commissioners.⁵
- However, few people with cancer say that they were offered or signposted to formal domiciliary care (unless already receiving such support before the cancer diagnosis)

or respite care. With adequate signposting to available support often lacking, providers think more people with cancer may be eligible for their support. However these people are not being identified, assessed and referred for support by the relevant professionals.⁵

- Only one in three carers have heard of carers' assessments and only one in 20 have actually had one. More than two in five (44%) have not heard of it at all.³
- More than a quarter of people living with cancer (26%) say they feel abandoned by the system when they are not in hospital.⁴

People affected by cancer do not have adequate information about the support available

- More than a third of people with cancer do not feel confident about how and where to access social care and support, describing the system as confusing.
- The Macmillan *Social care for cancer* report highlights a low awareness of available services at an individual level and a lack of understanding around eligibility.¹

- People with cancer can find it demeaning when family members and friends have to help them with dressing or bathing. They would prefer professional support. However, they are not always clear whether they would be eligible for such support or how to gain access to it.
- Providers highlighted that people with cancer are not aware of, or don't ask for, the kind of help that may be available to them.
- People are largely unaware of any financial support available other than state benefits. People affected by cancer state that they did not think to ask for information in this area.
- The Macmillan *More than a million* report states that 27% of carers do not know what support is available to them.³

Resources are limited, with services often lacking integration. People affected by cancer often do not identify themselves as meeting the requirements for support

Resources are limited with the support available varying greatly from region to region

- Limits on resources mean that many people are not getting the social care support they need. This can be due to the lack of available resources to commission more services, as well as the inflexible provision of existing mainstream services.¹
 - As social care in England is so under resourced, local authorities focus on people with 'substantial' and 'critical' needs, (defined under the Fair Access to Care Services (FACS) criteria). This leaves people with low or moderate needs without the support they require.²⁵ It is estimated that 72% of councils now only offer homecare services to people with needs rated as 'substantial' or 'critical'.²⁴ This also impacts on the carer, as services for people living with cancer will often indirectly support them.¹
 - Approximately 5% of carers say support does not exist in their area, indicating a postcode lottery for adequate support.³
- The under resourcing is mentioned by the NHS which highlights waiting lists for support and eligibility for social care.
 - Failing to support people living with cancer in the community can lead to the escalation of their conditions, and potentially to inappropriate hospital admissions. As an indication, of the 14,500 people living with cancer in hospital at any one time, 60% have been admitted as an emergency. This is at a cost of £2.9m a day to the NHS.²⁵

Services are not integrated meaning people affected by cancer are missing out on vital support

- Social care providers are also concerned that local authority social care commissioners see cancer as a health issue. And as such, they may leave the commissioning of appropriate support to PCT commissioners. Although joint commissioning arrangements are becoming more commonplace, the impact of these does not seem to have been felt yet by some providers, leaving people affected by cancer to fall between the gaps.¹

- People living with cancer and cancer carers rarely experience a consistent, integrated system of social support. 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. They may also not know how to access social workers, leading to delays in achieving assessments of social care need and subsequent access to services.²⁶

There is a lack of identification as a carer

- Carers may also miss out on assessments and services as they do not always identify themselves as carers and seek support.²⁷
- Only two in five carers (43%) actually identify themselves 'a great deal' or 'a fair amount' as a 'carer'. They are more likely to say this term does not describe them (51%) with 19% feeling they are not entitled to support.³

The social care market is growing, and it is a shared market with a high proportion of care provided informally by family and friends

Looking at the provision of informal social care for all needs not just cancer needs, about five million people provide informal care to family and friends. Between 73% and 81% of older people who receive help with activities receive only informal help.²³

The majority of care provision is not from formal services but by unpaid carers, mainly spouses/partners, adult children and other close family.²⁸

The census 2011 data showed the number of carers increased from 5.2 million to 5.8 million in England and Wales between 2001 and 2011. It would cost £87 billion a year to replace informal carer support with formal paid care. A total of 75% of people with cancer, or 1.5 million of the 2 million living with cancer in the UK, receives 'support in every aspect possible' from friends or family throughout their cancer journey. Only one in five cancer patients feel the needs of their carer are being met by social and health services.²

More than 1.1 million provide caring support to someone with cancer.²

The private social care market is increasing in line with demand, with a high proportion of care now delivered by private and third sector providers. The proportion of people funding their own care and the proportion of care occurring in the home is also increasing

There are more than 40,000 organisations delivering care in the UK. A high proportion of social care services are outsourced to private providers and constitute more than four fifths of the market.

Many local authorities/Health and Social Care Trusts have outsourced their own services to external providers, and almost 90% of social care services are now provided by private and third-sector organisations.²⁹

Of all the residential care places in England, 51% are commissioned by local authorities, 41% by individual consumers and 8% by the NHS. Of all home care contact hours, 60% are purchased by local authorities, 21% by individual consumers, 10% by direct payment holders and 7% by the NHS.²⁸

The proportion of individuals funding their own residential care services is increasing, while the proportion of local authority-funded residential care places is declining over time. NHS-funded places are also increasing. However, there are large geographical variations. In the south west of England, 53% of residents pay for their care compared to only 21% in the north of England.²⁸

The provision of home care rose significantly in the year 2011-2012. There were 6,830 domiciliary care agencies registered with the Care Quality Commission (CQC), an increase of 16% on 2010/11. At the same time, the number of residential care homes registered with the CQC decreased by 2.5%.¹⁸

The domiciliary/home care market in the UK is worth approximately £8.5 billion. It is estimated that the number of home care residents in the UK will increase by 1.4% from 418,000 in 2010 to 424,000 by 2015, driven by ageing demographics. In England, 87% of publicly-funded home care is now provided by the independent sector, compared to just 5% in 1993.³⁰

The government funding for social care will change dramatically in the next few years, but people affected by cancer will continue to fund a high proportion of their own care

Who	Current	Future
Government and local authorities	<p>Care needs are assessed by the local authority who assess the financial income and assets of a person with cancer to determine how much they can contribute to the costs of their care. This includes housing assets. People pay for their care until they have only £23,250 left, at which point state support kicks in.</p> <p>By 2022, public expenditure on social care and continuing health care for older people is set to rise to £12.7 billion in real terms. This marks an increase of 37% from £9.3 billion in 2010.</p>	<p>The government has announced changes to the way social care is funded, coming into effect in 2017 subject to the passing of legislation. The key features are:</p> <ul style="list-style-type: none"> • a cap on care costs at £72,000 – from 2016, the government will pay for care costs incurred by individuals over this level, equivalent to about £61,000 when compared to the 2010/11 prices used by Andrew Dilnot in his 2011 commission • a new means-test threshold of £123,000 – the government has increased the threshold where people can get help with their care costs from £23,000 to £123,000. This was recommended in the Dilnot report. <p>Individuals would continue to have their care needs assessed by local authorities to check they meet eligibility criteria.</p> <p>The Draft Care and Support Bill enhances carers’ rights to support, but it is not fully clear how charging arrangements will work.</p>
People affected by cancer	<p>A significant number of people fund their own care, with 45% of care home places in England occupied by people who do so. A fifth of people who receive care in their own homes are self-funding. Some people also pay top-up fees to bridge the gap between what their council will pay and what care providers charge.¹⁸</p> <p>The cost of replacing all informal care (not just for cancer) would be £87 billion. Currently there are two million people living with or beyond cancer.</p>	<p>If the supply of informal care is to keep pace with the need for care, the number of disabled older people in households receiving informal care would need to rise by 31%. This would be from approximately 1.9 million in 2010 to just over 2.6 million in 2022.³¹</p> <p>The number of people with cancer is set to double by 2030 indicating a doubling in the cost of any informal care provided. A report by the Free Enterprise Group (made up of MPs) wants to encourage a rise in this informal care.²⁵</p>

Funding for palliative care in England is changing, with a new model currently being piloted. This could lead to free social care at the end of life and an increase in the proportion of people being able to die in their place of choice³²

Current	Future
<p>Palliative care in England is supplied by a number of providers from the NHS and voluntary sector. There is a lack of integration and coordination between services, and the provision of palliative care varies between geographical areas.</p> <p>The lack of a clearly defined funding model and any national tariff means that block contracts, with some spot purchasing, are the most common funding mechanisms currently employed in palliative care services. This means that payments do not follow a person, and providers are paid regardless of activity, impeding commissioners from managing services' performance. The current system does not therefore ensure best possible value for money.</p> <p>PCTs vary in how much they spend on palliative care, with one PCT spending approximately £186 on specialist palliative care for each person who dies, while another spends £6,213. A total of 61% of all PCTs spend less than £1,000 on each person who dies.</p> <p>Wales</p> <ul style="list-style-type: none"> The Welsh Assembly established the All Wales Palliative Care Planning Group to determine how the needs of the 30,000 people who die annually could be better met. The recommendations were published in the Sugar Report (Palliative Care Report) in 2008 and the Palliative Care Implementation Board leads on implementing its findings. Dying Well Matters, an initiative encouraging feedback on palliative care services, was launched in 2009. <p>Northern Ireland</p> <ul style="list-style-type: none"> In 2010, the devolved government published a five-year strategy – Living Matters, Dying Matters – to extend access to palliative care to the 15,000 people who die each year. <p>Scotland</p> <ul style="list-style-type: none"> The Scottish Partnership for Palliative Care's action plan – Living and Dying Well – is designed to meet the needs of the 55,000 people who die in Scotland each year. 	<p>The review was asked to develop a funding mechanism for each person. The review recommends that once a person reaches the end of life stage, and is put on the end of life locality register, all health and social care should be funded by the state. It should be free at the point of delivery and people should be able to die in their place of choice.</p> <p>Seven adult pilot sites were identified to take forward the recommendations from the review. These will be funded for two years from April 2012 and will collect essential cost and activity data.</p>

Macmillan professionals provide vital support to people affected by cancer. This includes aiming to ensure that all the social care needs referred to them are met and that people at the end of life die in a place of their choosing

Macmillan professionals

In 2012, we reached 598,568 people through our Macmillan professionals, which combine Macmillan nurses, Macmillan assistant health practitioners and Macmillan doctors. However, we know that not all people affected by cancer will be reached through our Macmillan professionals.

Macmillan nurses help people living with cancer and their families receive essential medical, practical and emotional support. In 2012, we reached 478,600 people living with cancer through our Macmillan nurses. In addition, our Macmillan Nurses helped many more carers, family members and friends. In 2012, the average Macmillan nurse helped 144 people with cancer across the whole year.

Macmillan social workers work with community and social services agencies to help people manage the social and practical problems of living with cancer. They do this alongside a smaller number of Macmillan family support workers. In 2012, we reached an estimated 29,020 people through our Macmillan social workers. However, we know that not all people affected by cancer will have access to a Macmillan social worker.

Social workers supply a variety of support by activities including:

- providing psychosocial and emotional support to individual people living with cancer and their families
- facilitating and coordinating discharges from hospital
- giving benefits advice or referring people 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 practical ways such as 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.

Evidence indicates that the social worker plays an invaluable role in supporting terminally ill people with cancer to die with dignity in their preferred place of care. Qualitative feedback from key informants reveals positive views about the difference social workers have made. That is

to people living with cancer, their families and the specialist palliative care multidisciplinary team the postholder works closely with. Social workers are able to reduce the use of acute bed days by speeding up discharges and avoiding readmissions. They are also able to free up the clinical capacity of specialist staff to perform core functions.

Macmillan is in a position to provide a range of information and emotional support. Not all people affected by cancer will have access to these services due to geographical constraints, limited availability and lack of internet access

Information and emotional support

Macmillan Support Line

The Macmillan Support Line is staffed by cancer support specialists. They are here for everyone affected by cancer, whatever they need. They can answer questions about cancer types and treatments, provide practical and financial support to help people live with cancer, and be there if someone just wants to talk. In 2012, we responded to 148,826 phone calls, emails and letters via the Macmillan Support Line – that’s an average of more than 2,862 a week.

Macmillan’s online community

The online community provides a forum for people affected by cancer to talk, share experiences and provide support. It allows them to join support groups and gain peer and emotional support

Macmillan information resources

Macmillan produces a wide range of publications in a number of formats specifically for people with cancer, and their family and friends. We make these available free of charge to people affected by cancer, as well as the professionals and volunteers who work with them. In 2012, we reached an estimated 3.7 million people affected by cancer through our information resources.

Macmillan website

Our website features a number of elements. It offers high-quality cancer information and an online community where people can chat and support each other. In addition, it provides information on how Macmillan and other organisations can provide emotional, practical and financial support.

In 2012, the ‘source of support’ sections of our website helped an estimated 4.7 million people affected by cancer in the UK.

Macmillan cancer information and support services

A visit to a cancer information and support centre provides people with the chance to ask questions and talk through their concerns with Macmillan information professionals and trained volunteers. The centres hold booklets and leaflets about cancer, and information on financial support. Many centres have benefits advisers available to help, some offer complementary therapies. Macmillan also funds the design, construction and furnishing of hospital and community-based cancer information and support centres. In 2012, we achieved 353,831 interventions with people affected by cancer through our UK network of Macmillan information and support services.

Macmillan mobile information and support services

Our mobile information and support services tour the UK throughout the year, offering free, confidential information and support to people in their communities. Anyone is welcome, whether they have a cancer diagnosis, are visiting on behalf of a friend or relative, or are worried about cancer. The services are staffed by Macmillan cancer information and support specialists who offer a wide range of information and support tailored to a person's individual needs. In 2012, our four Macmillan mobile information and support services reached a total of 58,620 people affected by cancer across England.

Macmillan befriending service

Our Macmillan befriending service offers emotional, social or practical support by matching a trained 'befriender' to someone affected by cancer.

Macmillan counsellors

These provide psychological and emotional counselling support, including bereavement support, to people affected by cancer including people with a diagnosis, carers and relatives.

Recognising the hardship many people affected by cancer face, Macmillan offers a wide range of financial support and information

Financial advice and support

Macmillan benefits advisers

Our benefits advisers work in a variety of settings, for example in Citizens Advice Bureaux, Macmillan information and support centres, local councils or hospital environments. They provide essential welfare benefits advice and casework support to people affected by cancer. They can work as single posts or in larger teams to provide support across a wider area. A Macmillan benefits adviser offers specialist advice on entitlement to benefits, tax credits and grants. They can also provide assistance with claims and representation at reviews and appeals. In 2012, our national network of face-to-face Macmillan benefits advisers reached an estimated 112,820 people affected cancer, identifying approximately £191m in benefits for people affected by cancer. However not all people affected by cancer are reached by this service.

Macmillan Support Line (financial support element)

Our Macmillan Support Line has a specialist team of phone-based Macmillan benefits advice experts who offer specialist advice to help ease money worries for people affected by cancer. This includes

providing information on benefits, tax credits, grants and loans. In 2012, our Macmillan Support Line benefits advice experts reached 26,803 people affected by cancer across the UK, identifying around £38.6m in benefits.

Financial guidance service

Our financial guidance service provides information and guidance on issues including pension options, insurance (such as life and critical illness insurance), mortgage options, financial planning, or even just explaining financial jargon. In 2012, it provided 10,546 people affected by cancer in the UK with advice, identifying £7.5m in financial gains.

Macmillan Grants

Macmillan Grants help people with cancer on low incomes to meet costs that can arise from the condition and its treatment. A Macmillan Grant is a one-off payment for adults, young people or children with cancer, to cover a wide range of practical needs. This can include heating bills, extra clothing or a much needed break. In 2012, 30,611 people with cancer received Macmillan Grants, totalling around £8.5m. In 2012, an average of 588 people received a Macmillan Grant every week.

Macmillan recognises the role of carers, friends and family and is developing a volunteer-led service to help meet the needs of people affected by cancer

Support for carers and friends and family

Support for carers is very similar to the support offered for people living with cancer.

Carers can access:

- Information and emotional support via our Macmillan Support Line, website, mobile information units and cancer information and support services.
- financial help and benefits advice
- peer support – through the online community and self-help and support groups
- learning and development opportunities through Learn Zone
- information resources on subjects including employment rights
- a Macmillan bereavement scheme which involves supporting someone affected by cancer so they can grieve, and helping them cope with the loss of a loved one.

Direct volunteer services for all people affected by cancer

The direct volunteer service will establish and support new volunteering schemes to deliver emotional and practical support to people affected by cancer. This will involve:

- emotional support such as regular visits to offer a friendly face and/ or to befriend or buddy someone affected by cancer
- practical support such as help in the home, or with gardening, driving, picking up the children from school or doing the shopping.

Opportunities for secondary analysis

We have identified several opportunities for further analysis from several large national quantitative surveys. The large-scale surveys record a variety of information on health and social care.

Health Survey for England

In 2011–2012, this survey captured information from 219 people with cancer. Conducted annually, the survey includes all socio-demographic breakdowns and looks at general health topics and social care needs. These include formal needs such as activities of daily living while a new module will also capture the provision of informal support. It also records mental health and wellbeing, as well as use of health services.

Understanding Society

The survey is a longitudinal study with the same people interviewed each time. Of the 100,000 individuals interviewed each year, 1,623 respondents have or have had cancer. It looks at health, standards of living, social networks and support. Capturing all demographics, there is also an ethnic minority boost within the sample. Social care needs include capturing informal care such as if you care for another person in a household, and for how long and whether this affects paid work. It also looks at social support and contact from friends and neighbours.

English Longitudinal Study of Ageing

This survey is about the lives of people aged 50 and over (and their partners). It is conducted every two years. With 981 respondents with cancer, you can track when the diagnosis was made. It captures health, wellbeing, household and family structure and social networks of support, also looking at the defined needs of activities of daily living.

Both longitudinal studies present the opportunity to look at changing needs over time.

Research commissioned by Macmillan with MRUK

From this insight research it is clear that people affected by cancer are not always having their social care needs met, and that there is no one piece of research that showcases the scale of unmet need. There is therefore a need to establish the prevalence of the social care needs of people affected by cancer across the whole of the UK.

Macmillan has therefore commissioned large scale research with the independent agency MRUK, to determine the scale (size and detail) of unmet social care needs in people affected by cancer. The research is due to be published in March 2014.

The results will then guide our campaigns, policy calls and how we can all best support the social care needs of people affected by cancer.

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Cancer is the toughest fight most of us will ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But they don't have to go through it alone. By working together, we can all be there for people affected by cancer every step of the way.

Our cancer support specialists, benefits advisers, financial guides and cancer nurses are available to answer any questions people affected by cancer might have through our free Macmillan Support Line on **0808 808 00 00**. We're open Monday to Friday, 9am to 8pm.

Or you and your colleagues can visit **be.macmillan.org.uk** to order Macmillan's specialist cancer information for the people you support.

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