Identifying Cancer Carers and Signposting Them to Support

Background and guidance
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Introduction

There are almost 1.5 million people in the UK looking after friends or family members with cancer – yet more than half don’t receive any support.¹ One major reason for this is that many people who take on a caring role don’t identify themselves as a ‘carer’. You and your colleagues can help to identify these cancer carers and signpost them to the support they need.

Macmillan’s definition of a carer is ‘someone who provides unpaid support to a family member or friend with cancer who couldn’t manage without this help’.

Carers tell us that supporting someone with cancer can have a big impact emotionally, physically and financially. It can affect their own health, mental well-being, working life and relationships. Support is available to these carers, but often they don’t know about it or how to access it. Healthcare professionals are ideally placed to identify cancer carers and signpost them to this support. Around 1 in 5 carers say they were identified either by a hospital doctor or hospital nurse and 8% were identified by other hospital staff.¹ Hospital staff have a vital role to play in identifying cancer carers, to:

• enable carers to look after their own health and well-being
• prevent carer breakdown and potential hospital admissions for the person with cancer and/or their carer²
• enable carers to better support the person with cancer
• support working carers to remain in employment
• reduce the financial impact of cancer on the carer and the person with cancer
• reduce isolation and support carers to maintain their social life and relationships
• enable carers to continue in their caring role if they choose to.

There is now legislation and government policy that aims to provide greater support to carers.

In England, the Care Act 2014 requires local authorities and health bodies to work together to identify carers and for the first time gives carers the same legal right to a needs assessment and support as those that they care for.

In Scotland, the Carers (Scotland) Act 2016 puts a duty on Local Authorities to prepare an adult carer support plan for identified carers.

And in Wales, The Social Services & Well-being (Wales) Act 2014 places specific duties on local authorities to offer carers their own needs assessment and meet their eligible needs.

All the legislation aims to improve outcomes, reduce hospital admissions and prevent future care and support needs.

Macmillan wants to work with healthcare professionals to ensure every person with cancer and their carer(s) has a positive experience of care and support. This document, which was co-produced with professionals, sets out what hospitals can do to identify and support cancer carers. It is accompanied by short practical guidance for healthcare professionals, Supporting carers of people with cancer which can be found at macmillan.org.uk/supportingcarers
Cancer carers in the UK

• There are almost 1.5 million people aged 15 or over caring for someone with cancer in the UK. This number has soared from 1.1 million people in 2011 and will continue to grow as the number of people diagnosed with cancer increases.

• 68% of cancer carers are female, 32% male.

• Half of cancer carers are in employment, and more than 110,000 ‘sandwich generation’ carers also have dependent children living at home.

• Around a third of cancer carers (35%) support someone who is currently having treatment. The long treatment cycles for cancer can mean carers spend significant amounts of time travelling and at hospital.

• 63% of cancer carers live apart from the person they support, which increases travel costs and time away from home and work.

• Most cancer carers are looking after a family member, usually a parent (30%) or a spouse or partner (17%).

• Cancer carers give an average of 17.5 hours of support each week, equivalent to more than two working days.

• More than one in five (38%) cancer carers perform healthcare tasks, such as giving injections, administering medication and changing dressings. More than four in ten cancer carers (45%) have not received any information or training from a healthcare professional on how to perform these tasks.

Cancer carers also provide a wide range of other support, including personal care, transport to hospital, liaising with professionals, shopping/collecting prescriptions, emotional support, and domestic help. Without this support, many people with cancer would be unable to cope with their illness and treatment regime.

Carers have a tendency to put the person they are caring for first, and may find it difficult to recognise and attend to their own needs. In addition, despite all they do, many people who take on a caring role don’t identify themselves as a ‘carer’ and miss out on support as a result.

‘I am a registered nurse but I cared for my friend simply because she is my friend. It would not occur to me to look for financial or other help.’

Female carer, 70

All stats in this section taken from Estimating the population of cancer carers in the UK YouGov/Macmillan Cancer Support, 2016, unless otherwise referenced.
Impact of caring for someone with cancer

Caring for someone with cancer can impact on many aspects of a person’s life.

• **Emotional well-being/mental health:** up to 70% of cancer carers report some form of emotional impact. 51% experience stress, 45% experience anxiety and 26% experience depression.

• **Physical health:** cancer carers report that caring causes exhaustion, sleep problems, digestive issues, reduced fitness, weight problems and back pain. Carers may delay seeking treatment for their own health needs due to a lack of time or replacement care.

• **Working life and finances:** many carers have to reduce their hours or give up work altogether. The extra costs of caring (including travel to and from hospital) combined with reduced household income can cause huge financial strain.

• **Social life and relationships:** carers may have less time to spend with other family members and friends, which can lead to isolation and loneliness.

Lack of support for carers can lead to a need for increased support from health and social care services, both for the carer and the person they are caring for.

― ‘Cancer consumes the patient and takes over their lives, that then radiates out to the entire family, then friends, it is as if you have nowhere to hide from it yourself which causes anxiety and feelings of being low.’

**Female carer, 50**

― ‘Dealing with uncertainty re: treatment and its implications creates anxiety. Having a good network of friends, family and empathic professionals is very helpful, and we do have that.’

**Male carer, 78**

― ‘I’m feeling overwhelmed with the responsibility of being a carer, wife, mother and now being the breadwinner, working part time in a demanding, pressured and stressful job on top of the stress which the cancer diagnosis has given rise to.’

**Female carer, 58**

All stats in this section taken from Estimating the population of cancer carers in the UK YouGov/Macmillan Cancer Support, 2016, unless otherwise referenced.
There is a range of support available for carers from both the statutory and voluntary sectors, although many cancer carers are unaware of this. This support includes Carers Assessments from the local social services/social work department. These are a gateway to practical support such as carers breaks and help at home. Support available also includes advice on financial help and employment rights, and support from GPs such as annual health checks and flu jabs.

For more information on the support available and how to signpost carers see page 10.

The Cancer Strategy for England stresses the importance of “valuing informal carers and volunteers as part of cancer care teams, and ensuring they have the skills, knowledge and support to provide care.”

33% of cancer carers say they haven’t felt valued and included by professionals as part of the team providing care, and 49% say they haven’t felt involved in planning for hospital discharge. Carers tell us that, prior to discharge, they need training from healthcare professionals in healthcare tasks they may need to perform at home. This includes administering medication, correct use of equipment and patient handling techniques.

‘It is very emotionally draining. It saps all the joy out of your own life and makes it hard to be positive with others. It doesn’t have to be like that. Proper information and communication from medical, nursing and caring staff, involvement in decisions and inclusion would make all the difference.’

Female carer, 58

Top types of support carers say they need

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<tr>
<th>Support Type</th>
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<tr>
<td>Someone you can talk to/emotional support</td>
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<tr>
<td>Information and advice on the support available</td>
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<tr>
<td>Financial/benefits advice and information</td>
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<tr>
<td>Financial benefits, tax credits, grants</td>
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<tr>
<td>Information about cancer and it’s treatment</td>
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<tr>
<td>Help with household chores</td>
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‘There is help, the problem is finding it.’
Female carer, 80
Barriers to identifying and supporting carers – and suggested solutions

The complexity of caring

Caring relationships can be complex, and someone with cancer may be supported by a number of people who provide different levels of care. When identifying and supporting cancer carers, it is important to consider:

• ‘co-caring’ relationships: these are common among older couples, where both may have health problems and care for each other

• carers who develop cancer themselves: for example, a parent caring for an adult child with learning difficulties, who may themselves take on a caring role when their parent-carer develops cancer

• young carers: there are an estimated 700,000 young carers in the UK (aged 18 or under). Taking on a caring role can affect a young person’s education, health, and personal development. Support for young carers should be a part of support provided for the whole family e.g. via a referral to the appropriate agencies. Young carers can also be signposted to young carers’ projects with their parent’s permission. For further details see page 13.

Talking about caring

The term ‘carer’ is used to describe a range of support available to those who have taken on a caring role, including Carers Allowance, Carers Assessments and breaks for carers. Carers themselves, however, tend not to identify with the word – over half (55%) would not personally describe themselves as a carer. People with caring responsibilities may be resistant to the term ‘carer’ because:

• many see themselves in terms of their relationship with the person they care for e.g. as a wife, son, partner or friend

• it suggests a change in their relationship, and reminds them that their loved one is ill. The person they care for may feel the same way

• they are unsure what it means and may think it refers to a paid care assistant

• the term and concept of a ‘carer’ doesn’t exist in some languages and cultures.

Similar issues arise when talking about ‘caring for’ someone. These barriers can be overcome by using alternative language such as ‘looking after’ and ‘supporting’. It’s preferable to ask ‘do you look after someone’ rather than ‘are you a carer?’
Language and culture

Some carers and the people they care for may be reluctant to seek help from outside their family or community because it is seen as ‘taboo’ to do so. Or they may prefer to receive help from within their own community, for example, through a faith group. Language can also be a barrier, as the carer’s first language may not be English, or they may be acting as an interpreter for the person with cancer.

Health bodies should make links with relevant local community organisations in order to signpost carers to appropriate support. Training for professionals about identifying and supporting carers should include working with diverse communities.

It’s important that information for carers is made available in relevant languages, and that interpretation services are offered. In Wales, all information for people with cancer and their carers should be offered in both Welsh and English, in line with the Equality Act.

Practical barriers

Even with the best intentions, professionals cannot identify and support carers if not given the time, resources and support to do so. It’s important that each hospital has a carers policy, and systems in place to facilitate the process of identifying and supporting carers. Professionals have highlighted several challenges here:

- **Lack of time** - Both professionals and carers highlight the value of having time together to talk about the carers own health and support needs. Heavy caseloads, however, can make it difficult for professionals to consider the needs of another, or several other, individuals as well as those of the person with cancer. The short guidance produced by Macmillan is designed to enable quick and easy signposting to services that can provide more in-depth support, including Macmillan Cancer Information and Support services and local carers’ centres.

- **Lack of privacy** - Carers may not feel able to be completely honest about how they are coping unless they can have a private conversation. Often, there are no private spaces or quiet rooms available for professionals and carers to use. Where possible, an appropriate space should be allocated where carers are able to speak freely about their needs and concerns.

  Short practical guidance on identifying and supporting carers is available to download at macmillan.org.uk/supportingcarers

‘Identification doesn’t mean labelling someone as a carer or pressurising them to access support they don’t want – rather it’s about helping carers to understand their role and know that support is available if and when they need it.’

Charlotte Argyle, Carers Support Programme Manager, Macmillan Cancer Support
Confidentiality and data protection

Data protection and patient confidentiality guidelines should be adhered to at all times, but carers can find data protection a barrier to looking after their loved one. Sharing information with carers is particularly important at transition points, such as hospital discharge. Carers should be included in discharge planning, to ensure they know what to expect and are able to cope. Information sharing can be facilitated by putting processes in place to gain patient consent as early as possible for the carer to be included in conversations about their condition. For example, County Durham has introduced a system which makes it compulsory for professionals to ask their patients for consent to share information about their condition with their carers (SystmOne).

Carers are often an invaluable source of information about the person they are caring for. Working in partnership with both the carer and cared for will improve outcomes for all parties involved, including professionals.

‘The care and support given to the patient by the hospital has been excellent. The arrangements about putting in place the adjustments and social care for when he returns home have been good, but there has no clarity about what provision would be made and what would be left up to others (such as ourselves) to provide. There are gaps (e.g. cleaning, laundry etc) which could have been arranged earlier if we had been kept properly informed.’

Male carer, 59
Section 5: Identifying and supporting cancer carers

Healthcare professionals, including ward staff and allied health professionals, have a key role to play in identifying cancer carers and signposting them to support. This is essential, because currently very few cancer carers come into contact with the social care system, which has statutory responsibility for carers support.

Local authorities are responsible for identifying carers, assessing their needs and enabling them to access support. However, only one third of cancer carers have heard of the local authority Carers Assessment and only 5% have actually had one and receive support.1 Cancer carers most often present in healthcare settings, so you and your colleagues are ideally placed to identify and signpost them to support. Someone with cancer may be cared for by different people at different stages, and carers’ needs may change throughout the cancer journey. It is important to recognise cancer carers and their needs at all stages of the cancer pathway.

**Diagnosis**
Ideally, carers should be identified at diagnosis – the vast majority of carers (78%) started caring early in the person’s cancer journey; when they were diagnosed with cancer but had not yet started treatment.1 Friends or family members may not yet have taken on a caring role, but it’s best for them to have information about the support available in case they need it later on.

**Undergoing Treatment**
A third of cancer carers are looking after someone undergoing treatment.1 The person with cancer may develop care needs during treatment, as well as needing help getting to hospital. The carer may be the person who accompanies the patient to appointments and treatment sessions.

**Emergency or Planned Admissions to Hospital**
Emergency or planned admissions to hospital can mean the person with cancer has developed care and support needs. Their carer(s) should be treated as an expert partner in care, and involved in the care planning process.

**Hospital Discharge**
Hospital discharge is another key opportunity to identify carers and involve them in discharge planning, and signpost them to support for their own needs.

**Living with and Beyond Cancer**
People living with and beyond cancer may be living with long-term/late effects of their cancer and its treatments and have ongoing care and support needs, which will often be met by allied health professionals such as physiotherapists. Almost 1 in 5 (18%) cancer carers are looking after someone living with the long term effects of cancer and its treatment.1 If staff come into contact with people living with and beyond cancer, it’s helpful to check if someone close to them is still performing a caring role and needs support.

**End of Life**
If the patient becomes terminally ill, it is essential that their carer or carers are identified and signposted to support. At the end of life phase, the support needs of both the person with cancer and their carer(s) will increase and change. It’s important to check that the carer(s) are aware that additional support may be available, especially if they are caring for someone dying at home.
What hospitals can do to identify and support cancer carers

• Appoint a carers champion for the hospital (and individual wards as appropriate), with responsibility for sharing this guidance and good practice with staff.
• The champion could collate and maintain directories and resources for carers, and arrange awareness training for staff (ideally involving or delivered by carers).
• Carers champions for individual wards or services could work with colleagues and carers to create a carers’ information pack. This could include:
  1. details of the ward/service and named contacts, including for out of hours
  2. information about discharge planning procedures and post-discharge support
  3. details of local and national support services for carers
  4. information about cancer, and support for cancer carers – all available from Macmillan at be.macmillan.org.uk/carers
• Include policies about working with carers in induction sessions and packs for new staff, for example protocols for hospital discharge, confidentiality and sharing information. You could also include Macmillan’s short practical guidance for identifying cancer carers available from be.macmillan.org.uk
• Include carers in discharge planning – not only to ensure the person with cancer is supported at home, but also to ensure their carer knows what to expect and is able to cope. Information sharing can be facilitated by putting processes in place to gain patient consent as early as possible for the carer to be included in conversations about their condition.
• Where possible, allocate a private space where carers are able to speak freely with professionals about their needs and concerns.
• Provide staff and volunteers with access to training on communication skills, working with carers and diverse communities.
• Promote a culture where carers are recognised and valued as part of the team providing care.
• Include references to carers in information for people with cancer, to help them recognise that someone close to them may have a caring role.
• Form strong links with social services/social work teams and voluntary/community services in the area, and encourage all staff to do the same. Make contact details for carers’ support services easily accessible, for example through a directory of local services.
• Consider involving hospital volunteers to help with supporting cancer carers.
• Participate in Carers Week – an annual awareness week raising awareness of carers and the support available to them. Visit carersweek.org for more information.

• Signpost carers to free flu jabs through their GP or pharmacist to help protect themselves, and the person who’s being treated for cancer. This can help carers to recognise they have taken on a caring role, and access the support available.

• Promote Macmillan’s support for cancer carers, including our range of publications and leaflets specifically for carers of people with cancer. These are available at be.macmillan.org.uk, where you can also create publicity materials such as posters.

**Working with other services and professionals**

It’s important to establish links with local services and networks so that all staff are confident to refer carers on for support. Many services accept self-referrals or you could make a referral on behalf of the carer with their permission, e.g. to social services/social work.

There may also be support available for cancer carers from other health professionals involved in the patient’s care, including the clinical nurse specialist, community nursing team or hospice. Check and liaise with them about signposting the carer(s) to support.

You can also encourage the carer to tell their GP, and the GP of the person with cancer that they are a carer.

‘Ideally at diagnosis, carers will have the opportunity to ask questions and have their concerns identified’

*Healthcare professional*
Where to signpost cancer carers

Information and support from Macmillan

Macmillan provides information and practical and emotional support for carers of people with cancer. This includes:

• comprehensive information online at macmillan.org.uk/carers
• a range of free publications specifically for cancer carers available to order at be.macmillan.org.uk/carers
• information for working carers, including a guide to their rights at macmillan.org.uk/workandcancer
• emotional support via the Macmillan Support Line – 0808 808 00 00
• financial support online or via the Macmillan Support Line
• an online community for peer-to-peer support from other cancer carers at community.macmillan.org.uk
• a range of free courses, workshops and e-learning opportunities for cancer carers, accessible through learnzone.org.uk
• local Macmillan services including cancer information and support centres, support groups and volunteer services at macmillan.org.uk/inyourarea

Visit be.macmillan.org.uk to order our leaflet for cancer carers ‘Supporting a loved one through cancer?’ which gives details of all of the above.

Information and support from other sources

• Some trusts may offer support for cancer carers, such as financial help with travel and parking costs. The Trust’s PALS team will be able to advise on what’s available. In Wales contact the local Community Health Council, and in Scotland the Patient Advice and Support Service.

• Carers are entitled to a Carers Assessment from their local council. This is carried out by their local social services/social work department to identify the carer’s needs, and what support they may be entitled to. Your hospital should have a referral procedure or ask a social worker how to do this. Always ask the carer’s permission first to make the referral. Carers can have an assessment of their needs and get support from the local authority/council even if the person with cancer doesn’t want an assessment of their own needs. In Scotland, the Carers (Scotland) Act 2016 puts a duty on local authorities to prepare an adult carer support plan for identified carers.

• Carers UK provides expert advice and support for all carers throughout the UK via their support line and website. Call 0808 808 7777 or see carersuk.org

• For local support, see also Carers Wales at carersuk.org/wales and Carers Scotland at carersuk.org/scotland

• Carers Trust provides a network of local support for carers, including carers centres and Crossroads respite services. Details of local services can be found at carers.org
It may be helpful to collate a directory of local and national sources of support relevant to the cancer carers you work with, including organisations listed above and the Local Authority/Council.

Other sources of national support include organisations focusing on specific cancer types e.g. breast, bowel.

Sources of national support for the emotional impact of caring and support with mental health e.g. Anxiety UK, Samaritans, Mind.

The NHS provides online advice and information for carers at:
  - nhs.uk/carersdirect
  - wales.nhs.uk/carers
  - show.scot.nhs.uk

Local community groups and organisations may be able to offer support for carers, including those from minority communities. For more information see:
  - engagetoolkit.org.uk
  - nhs.uk/CarersDirect

Older carers may be able to access support from their local branch of Age UK. For more information, visit ageuk.org.uk or call 0800 678 1174

Citizens Advice provides advice and help with a range of topics including legal, money and housing problems. For more information see citizensadvice.org.uk

St John Ambulance and the Red Cross can provide training on moving and handling, first aid and other practicalities relevant to carers.
  - sja.org.uk
  - redcross.org.uk

The National Council of Palliative Care provides support for carers of people at the end of life via the Dying Matters website dyingmatters.org

‘Find Me Help’ is a comprehensive UK-wide directory of local support services for people at the end of life and their carers: help.dyingmatters.org

The earlier you can signpost a carer to support, the better. Their needs and situation will change as the illness of the person they care for progresses, so check in with them regularly to see if they need any additional information or support. Remember to document the carer’s details, and action taken, in the patient’s nursing/medical notes and other relevant systems.

How Macmillan is helping to identify and support cancer carers

As well as offering comprehensive support for cancer carers and guidance for professionals, Macmillan campaigns to make sure carers in the UK who look after a family member, friend or neighbour with cancer get the support they need. Our research helps us, and others, understand the needs, numbers and experiences of carers and we work with government and politicians to improve support. Our report ‘Under Pressure: the growing strain on cancer carers’ shows how friends, family members and neighbours who look after someone with cancer are coming under more pressure than ever before.

For more information visit macmillan.org.uk/carestrategy
References

1 Estimating the population of cancer carers in the UK YouGov/ Macmillan Cancer Support, 2016

2 Carer breakdown is defined as when the carer is no longer able to maintain their caring role due to fatigue, ill health, emotional strain etc.

3 Sandwich generation carers are defined as those caring for a parent with cancer while still having children living at home.

4 YouGov survey of 2,002 UK cancer carers, September 2015

5 bbc.co.uk/newsbeat/11758368
As a professional, you know cancer doesn’t just affect the people you support physically. It can affect everything – their relationships, finances, work. You may feel that there aren’t enough hours in the day to spend as long as you’d like with them, or to answer all their questions.

Macmillan can help, whether it’s offering additional benefits advice, guidance on returning to work, or helping people make plans for their future. We can help you give them the support they need to feel more in control of their lives.

Visit [macmillan.org.uk/profs](http://macmillan.org.uk/profs) to find out more.

And let your patients know they can contact us free on 0808 808 00 00 (Monday to Friday, 8am – 9pm) if they need additional support.