



**WE ARE
MACMILLAN.
CANCER SUPPORT**

DO YOU CARE?

Making identification and support
for carers a priority

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Foreword

Across the UK, at least 1.1 million people are currently caring for a friend or family member with cancer¹. As the number of people living with and beyond cancer continues to rise, from two million to four million by 2030², the number of carers is also rising.

Sadly, many people caring for someone with cancer remain hidden. They care in isolation, unaware of support services that may be available to them.

We need to take action now. We must ensure that every person caring for someone with cancer is supported to look after their own wellbeing while providing such vital care.

Carers do not always self-identify or associate with the term 'carer'. They also don't often come into contact with social or voluntary services that could help. It is therefore essential that health and social care professionals are proactive in recognising when a person may be caring for someone with cancer. They can then signpost these individuals to local information and support. Better identification and signposting is crucial not only for cancer carers, but for all 6.5 million carers UK-wide³.

As someone who once was a carer, looking after my partner, John, when he had cancer, I know the pressure that carers face. Dealing with the practical and emotional demands of looking after a loved one, while doing my best to remain positive and hold things together left little time to focus on my wellbeing. There were times when I felt lonely and anxious and, despite support from family and friends, I didn't always feel able to express my worries.

Identifying carers is the first step to providing them with the support they need to maintain their own mental and physical health and wellbeing. It is vital that we get this first step right.

We all have a role to play in raising awareness of the tireless effort of carers, and providing them with the support they need and deserve. Governments, health bodies, local authorities, private providers and the third sector need to work together to identify carers who have, or may develop, unmet needs for care and support.

Together, we can ensure every person caring for someone with cancer is properly supported, so that no one faces cancer alone.



A handwritten signature in black ink, appearing to read 'Juliet Bouverie'.

Juliet Bouverie
Director of Services and Influencing
Macmillan Cancer Support

Foreword

Every one of us is likely to take on caring responsibilities at some time in our lives. Carers play a vital role within the health and care system, supporting friends and family through some of the most difficult times they may face. Yet many don't identify as being a carer – they're just doing what they believe is right. They may not realise that there is support available to them, and they will not always know how to ask for help.

In the NHS, we come into contact with carers on a daily basis. They are the mothers, fathers, sons, daughters, siblings, spouses, friends and neighbours you see at appointments, during treatment, on the ward or in their own homes. They are the ones your patients may talk about. They are the ones caring at home, picking up prescriptions, changing dressings, providing much needed emotional support, and often neglecting their own health and wellbeing needs. They are vital to those they care for and the foundation of the health and social care system.

In the NHS we are often ideally placed to pick up on signs that someone may be caring and therefore have support needs of their own. We can help them to understand the role they play, the fact that it is okay to ask for support as a carer, and that there are services available to them. We aren't always good at this – but we can, and will, do more at every level to ensure carers are properly identified, supported and valued.

As a carer myself, when my husband was diagnosed with cancer and subsequently became terminally ill, I understand the issues carers can face. I did receive help and support but as a nurse, sometimes felt I should be able to cope without asking for it. Providing that support for carers is so important.

My vision is that every carer who comes into contact with the NHS has the support they need to look after themselves and their loved ones, and the recognition they deserve.

By listening to carers and patients, developing the right systems and support for professionals and an enduring commitment to the 6 Cs of compassion in practice, we can achieve this.

All NHS staff should feel confident in working with carers and foster working environments where looking out for carers is every day practice. Macmillan's guidance outlines how managers can create these environments. As professionals, we can adopt Macmillan's top tips, to ensure every carer we come across is given the chance to access the support they deserve.

Fundamentally I encourage everyone in the health and care system working with people affected by cancer to make a firm commitment to recognising, valuing and supporting those who care for others.



Jane Cummings
Trustee, Macmillan Cancer Support
Chief Nursing Officer for England

Executive summary

Currently, people caring for someone with cancer are not always being identified and therefore cannot access available support. We've been working with carers and health and social care professionals to unpick some of the reasons for this. Together, we've found some common barriers that prevent staff in health settings from identifying and supporting those who care for people with cancer.

This report should be read alongside the following publications:

- *Identifying cancer carers and signposting them to support* (guidance for hospitals)
www.macmillan.org.uk/carersguidance
- *Supporting carers of people with cancer* (short tips for health and social care professionals)
www.macmillan.org.uk/carertips

These publications explore what needs to happen nationally and locally to ensure professionals are able and supported to identify carers in health settings. We urge all trusts and health boards to adopt the guidance, and all professionals to use the tips.

We are also calling on governments and decision makers to play their part. By making carers a priority at every level, we can start to address the lack of identification and support and deliver better outcomes for people affected by cancer.

'I have no idea what or if there is any help available. I work full time, look after the house and care for a hubby who has terminal cancer.'

**Amanda, 36,
who cares for her husband,
north-west England**

Summary of recommendations

England

The government should:

- implement and monitor the Care Act and statutory guidance, and support the NHS and local authorities to work together to identify and support carers
- place a stronger legal duty on the NHS to identify carers.

The Department of Health should:

- ensure the refresh of the *Carers' strategy* highlights the importance of health bodies working with local authorities to improve early identification and support for carers
- ensure future iterations of the *NHS Mandate* prioritises the identification of carers.
- update guidance on joint strategic needs assessments (JSNA) so that all JSNAs must consider the needs of carers in the area and ways of identifying carers, particularly those with unmet care and support needs

NHS England should:

- deliver on the actions set out in *Commitment to carers*, and refresh and report against it annually
- monitor the impact of the national CQUIN on dementia, as a positive example of incentivising support for carers together with the needs of the patient. This is with a view to using this approach to incentivise commissioning of carers' services.

Health Education England should:

- ensure all health professionals have access to training on identifying and working with carers throughout their career.

Health and wellbeing boards should:

- ensure carers are meaningfully represented in joint strategic needs assessments and joint health and wellbeing strategies
- include approaches to identifying carers in plans under the Better Care Fund.

Trusts should:

- adopt Macmillan's guidance outlined in *Identifying cancer carers and signposting them to support*
- encourage professionals to tips outlined in *Supporting carers of people with cancer*

Wales

The Welsh government must ensure that the *Wellbeing of Future Generations Bill* clearly:

- sets out that strategic planning for carers will be central to the work of the new public service boards
- maintains a specific duty on health bodies to identify and support carers.

Local health boards and trusts should:

- continue working to identify and support carers (this is particularly important while the *Carers Strategies (Wales) Measure 2010* remains in place and in transitioning to any new arrangements)
- ensure that carers are consistently offered information and support in the Welsh language where they have indicated that this is their language of choice, in accordance with the *Welsh Language Measure 2011*.

Scotland

Health and social care partnerships formed by the *Health and Social Care Integration Bill* must integrate local government carer assessments with the health service as seamlessly as possible.

The recent Consultation on Carers by the Scottish government outlined some positive possibilities to improve the lives of carers.

While we await the outcomes and proposed legislation, Macmillan would like to see:

- the forthcoming legislation on carers to continue to support the use of the third sector in carrying out carers' assessments
- positive action to improve the number of carers' assessments taking place.



Carers need to be made a priority at every level so that professionals are confident and able to identify and support carers. Only then will carers receive the support they need and deserve.



Who is a carer for someone with cancer?

Macmillan defines a carer as anyone who provides unpaid support to a family member or friend with cancer who could not manage without that help. Caring can mean many things, including helping with personal care, providing transport, assisting with housework or performing healthcare tasks.

Across the UK, about 1.1 million people aged 15 and over are currently providing informal care for someone with cancer.⁴ This includes practical, emotional and financial support, and can have a substantial impact on the carer's own health and wellbeing. The total number of carers of people with physical and mental health conditions in the UK is 6.5 million.⁵ This number is set to rise to nine million by 2037.⁶

On average, cancer carers give almost 15 hours of care each week, though many provide in excess of 35 hours of care.⁷ Half of cancer carers are in employment, with approximately 50,000 working full-time while providing more than 35 hours of care a week. This is the equivalent of two full-time jobs.⁸

Carers in the UK make a major contribution to society. Their care is invaluable to the person who needs it, and the economic value for health and social care is an estimated £119 billion each year.⁹ Cancer carers provide care worth at least £14.5 billion each year.¹⁰

The most common motivation given by carers is that they simply want to provide this support or that they love the person or people they help. However, some may care out of obligation or a feeling of duty. Regardless of motivation, four in five cancer carers say they are affected in some way by the support they provide.¹²

Number of people currently caring for someone with cancer

▶ **ENGLAND - 905,000**

▶ **SCOTLAND - 83,000**

▶ **WALES - 55,000**



Carers are not receiving enough support

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Many carers are simply not receiving the support they need to maintain their own physical and mental health and wellbeing while providing care for someone else. Too frequently we hear of carers feeling isolated, lonely and anxious, and not knowing who to turn to for support.

Nearly half of cancer carers report that caring impacts on their emotional wellbeing and mental health. This includes feelings of stress, anxiety and depression. Carers also report that caring can cause tiredness and exhaustion, as well as sleeping problems, difficulties with digestion, reduced fitness, weight problems, and back pain from moving and handling¹³. However, demands on carers, and the impact caring has on them, are often overlooked by formal providers of care¹⁴.

Half of cancer carers report receiving no support at all¹⁵. Almost half of carers identify at least one form of support that would help them but that they are not receiving. The most commonly requested are information on caring and what to expect, training and advice on how to give care safely and effectively, and emotional support.¹⁶

Carers who are not supported can reach crisis point, developing or worsening their own health and care needs. This has negative impacts all round – for the individual and person they care for, and an added cost on the health and social care system. ‘Carer breakdown’ can lead to unplanned hospital admissions for the cared for, or the carer. It can also increase reliance on health and social care services if the carer becomes unable to provide care.

In a survey of 300 healthcare professionals, 89% agree that carers often neglect their own health when looking after someone with cancer. And 85% agree that not having enough support is the main reason for carers reaching breaking point and being forced to stop caring¹⁷. The care and support system must work to actively promote wellbeing and independence, and not just wait to respond when people reach crisis point.

We asked carers:
'What, if anything, would help/
would have helped you to care?'

This is what they told us...



The value of early identification and support for carers

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Identification involves asking questions about how the carer is doing, and making them aware that support is available, should they need it at any point. It does not mean labeling someone or forcing them to access support they do not want.

Health and social care professionals need to play a leading role in helping carers to understand their own support needs and directing them to information and services. Early and adequate support for carers can:

- improve health and wellbeing outcomes for the individuals being cared for
- improve health and wellbeing outcomes for the carers
- reduce unwanted hospital admissions, readmissions and length of stays
- reduce unwanted residential care admissions and length of stays.¹⁸

Working with carers can also lead to better outcomes for the person with cancer. During chemotherapy, for example, carers can observe and feedback on the progress of the person receiving treatment. They can monitor any side effects, and alert clinicians and nurses if any issues arise.¹⁹

Carers need to be identified at all stages of the cancer pathway. Not all carers will be visible or will even be carers at diagnosis point. Nonetheless, they should be told that support is available should they need it at any stage. Carers sometimes feel they do not need support when asked, however a later crisis could have been prevented if they had known about support systems that can be put in place.²⁰

Carers should also be included in discharge planning which can ensure that the person with cancer will be supported at home. It can also make sure that the person's carer or carers know what to expect and are able to cope. One in five cancer carers perform healthcare task such as changing dressings. Yet half of them (53%) are doing so without information, instructions or training from a health professional.²¹

'I don't care for myself. The guilt would be too much to handle.'

**Amanda, 36,
who cares for her husband,
north-west England**



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An over-reliance on carers to 'self-identify' means many continue to miss out on support

Over-relying on carers to self-identify can mean many carers remain hidden. If carers are not self-identifying, and health and social care professionals are not identifying them, carers will continue to miss out on information and support.

Less than half of people caring for someone with cancer identify themselves as a carer which means they often don't know that support is available. Male carers, those who provide less intensive support and those looking after someone younger than 65 are least likely to identify with the term.²² Once a person realises that they are acting as a carer, they are more likely to be able to find and access support services and assistance. This includes access to more formal support such as the Carer's Allowance.

Carers often do not think of their own needs. This is because they tend to focus on the needs of the person they care for or express guilt about looking after themselves first. This may be because they tend to focus on the needs of the person they care for, express guilt about looking after themselves, or feel they should be able to cope without support from others. Carers can therefore be passive about seeking support that may be available to them, and delay seeking help for their own health needs. This is particularly concerning given that carers generally have poorer health than non-carers. The 2011 England and Wales Census looked at carers who worked full-time and provided more than 50 hours of care weekly. It found that they were almost three times more likely than non-carers who worked full-time to report that their health was 'not good'.²³

For many, the term carer is seen negatively. It can be seen to suggest that the person they support has somehow failed by needing care, and imply burden. It also tends to focus on the physical act of caring, neglecting the fact that caring is also an emotion. The nature of the caring relationship can have a big impact on whether the carer feels able to seek support. The relationship between the carer and the cared for may be challenged if the cared-for person does not accept that is what is happening, while the carer thinks they are caring.²⁴

Making the term more accessible, and less stigmatised, may increase uptake of support services currently aimed at carers.²⁵ Governments, health bodies and local authorities need to continue to raise awareness of carers and remove the stigma from the term. Being a carer should not have to be a person's defining characteristic – they are an individual, a spouse, a child or a friend first. When embraced and used properly the term carer should be empowering.

'I didn't really consider myself his carer. I just thought of myself as his fiancée. As far as I was concerned, he wasn't well so I was looking after him.'

**Lisa, 35,
who looked after her fiancée Luke,
Essex**



The role of health and social care professionals in identifying and supporting carers



Much of the support available to carers can be accessed through local authorities or voluntary networks. However, many carers of people with cancer do not come in-to contact with their local authority or these services. Only 5% of cancer carers have had a Carer's Assessment,²⁶ the main gateway to statutory support for carers such as the carer's allowance and respite breaks. Of the very small number of cancer carers who have had a Carers' Assessment, the event that most often prompted this was a referral by a GP.²⁷

A 2013 Carers Week survey of more than 2,100 carers showed that only 35% of carers came into contact with their local authority during their caring journey. However, 71–85% of carers came into contact with health professionals including GPs, doctors and nursing staff.²⁸ But health professionals are only identifying one in 10 carers and GPs just 7%.²⁹

65% of professionals surveyed believe that carers of people with cancer are overlooked by the NHS.²⁴

Due to the nature of cancer and its treatment, carers of someone with cancer present more frequently in health settings, such as hospital wards, at their GP, or picking up prescriptions from their pharmacist. Carers may accompany the person with cancer to appointments with specialists or their GP. They may visit them while they are receiving treatment such as chemotherapy, or transport them to and from appointments. It is therefore vital that people working in acute health settings including hospitals, primary services such as GP practices, and community settings such as pharmacies identify carers and signpost them to available support. This should include referring them to their local authority for social services support.

Improving early identification of carers in health and social care settings is achievable and beneficial. The *Moffat project: preventing crisis for carers* demonstrates the ability to increase the early identification of new and hidden carers in health settings. This is through increased professional awareness and training, dedicated carer support workers and changes in organisational practice. Through the project, an extra 3,000 carers were identified and 3,500 health professionals received carer-awareness training.³⁰ Learning from this project and others of its kind should be implemented across the country. This can happen as responsibilities for local authorities and health bodies to work together to identify and support carers strengthen.

The bottom line is that carers will continue to miss out on information and assistance unless health professionals recognise them and their current and future support, health and wellbeing needs.

'Supporting carers in general practice is a win-win situation for everyone. For carers it improves their wellbeing, prevents illnesses and improves their ability to provide better care. For GPs and the NHS it leads to a reduction in referrals to social services for professional care at home.'

Dr Sachin Gupta,
GP and Royal College of GP Support Carers in General Practice Clinical Lead

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Improving identification and support for carers in health settings

Identifying carers can be difficult. Caring relationships are complex, and a person with cancer may be supported by a number of people who provide varying levels of care and assistance. As their condition develops, and they face different aspects of treatment, the impact on carers will also change. Caring responsibilities may be more intense at certain points, such as during chemotherapy or at the end of life.

Health professionals have told us of some of the barriers to reaching carers in day-to-day practice including:

The need to communicate carefully and avoid labelling someone with the term 'carer'. Simply asking 'are you a carer?' is unlikely to be effective in helping someone to access support, as many do not associate with the term.

Language barriers. It is important that information and advice is made available in different languages, and in different forms including online and in print. Interpretation services should also be offered. For example, in Wales, people with cancer and their carers whose language of preference is Welsh, should be offered NHS or social services' information in Welsh as well as English. This is in line with the Welsh Language Measure 2011.

Cultural barriers. Health bodies should be making links with local faith centres, schools and community groups to improve their population's awareness of what support they can receive. They should also increase their own knowledge of how to work with different communities and their attitudes to caring.

Lack of professional awareness. We recently surveyed 300 oncology nurses, oncologists and GPs. A total of 30% reported that they are not very confident in identifying and signposting carers.³¹ And only a third said they 'always' check whether a person accompanying the person with cancer at appointments is providing care and support.³² Professionals need the right training and support to feel confident in identifying carers and working with them.

'I felt totally involved and included in all discussions and decisions. No extra help is needed as I am in OK health, though knowledge support and advice available is reassuring.'

Peter, 72,
who cares for his wife,
north-west England



Unclear carers' policies. Only a third of oncologists, oncology nurses and GPs say their trust, health board, practice or clinic has a policy in place outlining how to identify carers and signpost them to support.³³ All health bodies should have a carers' policy in place, and someone to champion the needs of carers.

Lack of time. Caseloads are often overwhelming and thinking of the needs of another, or several other, individuals as well as those of the person with cancer can seem unachievable. Yet professionals and carers alike highlight the value of time together. They know that time spent talking about their own health and support needs and how they are coping with caring is beneficial.

'It was very frustrating. None of the care after leaving hospital was addressed to me and my mother given that we were the ones caring for my father. We felt excluded and as if we were not there.'

**Francis*, 25–34,
who cares for her father,
east of England**

Lack of privacy. It can be distressing to the person with cancer to know that their carer is struggling either emotionally, physically or practically. So a carer may not be completely honest about how they are coping unless they have a private conversation. Often, however, there are not private spaces or 'quiet rooms' available for professionals to use.

Confidentiality and data protection.

Some information about the person with cancer's condition cannot be shared with the carer due to patient confidentiality. Information-sharing with carers is very important, particularly at transition points, such as when a patient is discharged from hospital.

Not knowing where to refer carers to support. Close working relationships and links between NHS and social care are essential for effective carer identification and support. Staff should be encouraged to develop local contacts and networks, and trusts, practices and health boards providers should lead on this. For example, they could maintain a register of local services. *Identifying cancer carers and signposting them to support*⁷ includes useful contacts and carers' support services.

Macmillan is working with hospitals and GPs to improve identification and support for people caring for someone with cancer. *Identifying cancer carers and signposting them to support* explores ways of creating carer-friendly environments and supporting staff to identify carers and signpost them to support. Supporting carers of people with cancer can help professionals to recognise someone who may be caring for someone with cancer, and how to signpost to support.

'While the health professionals talked to me it was always in the context of the patient being present and so everything was happy-happy and upbeat. I was never spoken to alone and never prepared for the horrors I am now going through. Carers need to be counselled separately to patients so they can prepare for what is to come, particularly in the context of end of life care.'

**Mary, 54,
who cares for her husband,
south-east England**



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Governments must set the ambition for improvements in identification and support for carers

We need a whole system approach to identifying and supporting carers. Governments, local authorities, commissioners and providers must play their part in prioritising strategies that incentivise identification and support. An environment must be created in which professionals can identify, signpost and support carers at every stage along the caring pathway.

In Wales, Scotland and England there is now legislative recognition of the need for health bodies and local authorities to work together on this issue. Already, there are some excellent examples of professionals working across health and social care to meet the needs of carers in their areas. This needs to continue, and best-practice examples need to be shared and adopted.

England

In England, the Care Act 2014 sets a welcome ambition for parity of esteem between carers and those they care for. This includes an important duty on local authorities to identify carers with unmet needs for care and support. Macmillan and others have campaigned to ensure that this responsibility does not fall squarely on local authorities, but is met through cooperation between the NHS and local authorities.

Statutory guidance under the Care Act now recognises the role the NHS has to play in working with local authorities to identify carers with unmet care and support needs. In particular, those who may develop such needs. It is excellent to see this growing recognition of the need for early identification and support for carers. The Department of Health, the NHS and local authorities need to continue to champion carers' needs. They also need to work together, and with partners, to ensure the Care Act achieves its preventative aims.



The government should:

- implement and monitor the Care Act and statutory guidance, and support the NHS and local authorities to work together to identify and support carers
- place a stronger legal duty on the NHS to identify carers.

'From my experience of being a former GP, the NHS are the most likely people to be in contact with carers. There are examples of extremely good practice but unfortunately progress remains patchy in the areas where health professionals are perhaps most under pressure. Unless identification of carers is prioritised at all levels it will, unfortunately, tend to shuffle to the back of the pack and might be missed. Practitioners must have effective procedures to identify carers to ensure better care for those who they are caring for, and because it is the right thing to do'

Dr Sarah Wollaston MP,
Chair of the House of Commons Health Select Committee and former GP

The Department of Health

The Department of Health will play a crucial role in promoting and implementing the Care Act 2014 and championing the role and needs of carers. This includes delivering on commitments in its Carers' Strategy to improve support for all carers and help them to get the information, advice and help they need to stay healthy. The strategy refresh should build on work to date, and capture the need for cooperation in identifying carers. The Department should also be issuing relevant guidance to help others to meet the needs of carers. For example through the Mandate to NHS England and guidance on joint strategic needs assessments (JSNAs).



The Department of Health should:

- ensure the refresh of the Carers' Strategy highlights the importance of health bodies working with local authorities to improve early identification and support for carers
- update guidance on joint strategic needs assessments (JSNA). This means that all JSNAs must consider the needs of carers in the area and ways of identifying carers, particularly those with unmet care and support needs
- ensure future iterations of the NHS Mandate prioritises identifying carers.

'We know carers don't always recognise themselves as a carer and can remain "hidden" from services and miss out on support because of this. In Torbay we understand that a "whole system" approach is needed to support carers and that proactive identification is needed by the NHS. If we wait for carers to approach us, we may not engage until there is a crisis. Proactive identification is good practice, but national support is needed to spread this across the country. It should be made clear that identifying carers and signposting them to support is the responsibility of all health and social care professionals, not just local authorities.'

James Drummond,

Lead Officer for Integrated Services, Torbay and Southern Devon Health and Care NHS Trust

NHS England

Macmillan is delighted that NHS England is taking a lead on carers, with the widely welcomed publication of Commitment to Carers in May 2014. This important framework sets out 37 actions for NHS England, working with partners, to improve awareness and support for carers. It is vital that these actions are undertaken without delay and the commitments are reported against annually. NHS England should continue to facilitate best practice sharing and relationship-building across health and social care.

NHS England is also leading on a recently introduced enhanced service that aims to reduce the incidence of unplanned admissions. There is an expectation that, if done well, GPs will identify carers and include supporting their needs when developing care plans to reduce avoidable admissions to hospital. However, anecdotal evidence indicates that the enhanced service can be treated as a tick-box exercise with many areas not using it to improve support for carers.

NHS England must monitor commissioning incentives to find the most effective ways of improving identification and support for carers. For example, they could evaluate the impact of the new CQUIN on dementia, which includes a responsibility to identify and support the carer. This includes an annual carer health check, with a view to using a similar incentive to improve support for all carers.



NHS England should:

- deliver on the actions set out in *Commitment to Carers*, and refresh and report against it annually
- monitor the impact of the national CQUIN on dementia, as a positive example of incentivising support for carers, together with the needs of the patient, with a view to using this approach to incentivise services for all carers.

Health Education England

Health professionals need the skills and confidence to work with carers and help them to access available support. In shaping the future workforce, Health Education England has a key role to play in ensuring all health professionals have access to training on identifying and supporting carers, and for communicating with patients and their carers.



Health Education England should:

- ensure all health professionals have access to training, including continued professional development, on identifying and working with carers.

Health and wellbeing boards

Statutory guidance under the Care Act 2014 encourages Clinical Commissioning Groups (CCGs) and local authorities to work together. One way of achieving this is through health and wellbeing boards. They are well placed to use joint strategic needs assessments and joint health and wellbeing strategies (JHWS) to identify and plan to meet the care and support needs of the local population. It is crucial that carers are included meaningfully in JSNAs and JHWSs, yet currently this is not always happening.³⁴ A strong JHWS should reference actions to be taken to reach those groups, including plans on how to identify carers. To help with this, health and wellbeing boards could think about having a patient representative and a carer representative on their board.

All Better Care Fund plans should also detail local approaches to identifying and supporting carers, across health and social care, with the view to early intervention and support. This would prevent hospital admissions and improve outcomes for the local population.



Health and wellbeing boards should:

- ensure carers are meaningfully represented in Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies
- include approaches to identifying carers in plans under the Better Care Fund.

Trusts

Trusts should be creating carer-friendly environments, where professionals are properly supported to identify carers, and signpost them to local services and assistance.



Trusts should:

- adopt Macmillan's guidance outlined in *Identifying cancer carers and signposting them to support*
- encourage professionals to use tips outlined in *Supporting carers of people with cancer*

Wales

The Welsh government has recognised the seriousness of the identification challenge and taken steps to address it through legislation. There is now a statutory requirement on Local Health Boards (LHBs) and trust to lead on published strategies outlining how they intend to identify and support carers. This has led to initiatives such as the West Wales Hywel Dda Health Board's work with GPs to roll out an 'Investors in Carers' programme. LHBs and Trust across Wales have also undertaken carers' awareness training with frontline staff.

The Carers Strategies (Wales) Measure 2010 (Carers' Measure) placed the lead responsibility for identifying carers on LHBs/Trust recognising the crucial role of health bodies in this area.

This was the first legal duty given to the NHS in Wales to provide services to carers and set out the need for health services to recognise new carers quickly and support carers to look after their own health.³⁵

The Carers Measure will continue to be the key strategic planning mechanism for carers in Wales until April 2016 when it will be repealed. Macmillan Wales welcomes the fact that the Social Services and Wellbeing Act will introduce important new rights for carers in 2016. However, Macmillan Wales and the Wales Carers Alliance have concerns about the introduction of the new Act and the *Wellbeing of Future Generations Bill*. It is vital that the statutory duty for carers on LHBs and Trust does not get lost along with much of the detail from the Measure.



The Welsh government must ensure that the *Wellbeing of Future Generations Bill* clearly:

- sets out that strategic planning for carers will be central to the work of the new public service boards
- maintains a specific duty on health bodies to identify and support carers.

Local Health Boards and Trust should:

- continue working to identify and support carers (this is particularly important while the *Carers Strategies (Wales) Measure 2010* remains in place and in transitioning to any new arrangements)
- ensure that carers are consistently offered information and support in the Welsh language, where they have indicated that this is their language of choice, in accordance with the *Welsh Language Measure 2011*.

'The Carers' Measure has definitely engaged health bodies much more actively in the carers' agenda by having the statutory obligation to lead on the local carers strategies. There is still a long way to go but early signs are positive. On numerous occasions across Wales, I have heard professionals in health independently raise the importance of supporting carers. Our Wales office has received more enquiries from health. For example, we have had GPs' surgeries contact us for information they can display as "we have to provide information to carers now". Individual carers are being referred on to local carers services by GPs and other health professionals etc.'

Keith Bowen
Director, Carers Wales

Scotland



In Scotland, each Local Health Board has developed a Carer Information Strategy to identify and provide information and support to carers. NHS Education Scotland and the Scottish Social Services Council are working together with partners to develop core values, skills and knowledge. These will help staff across the whole health and social care workforce to work with carers.³⁸ Reports from Local Health Boards show success in this area, including increased referrals to support by NHS staff and improved carer awareness.³⁹

The Quality and Outcomes Framework in Scotland requires general practices to have a protocol for identifying carers and a mechanism by which to refer them to social services. This is a positive step, but may not deliver the results needed as there is no target for the number of carers identified and referred. Further, the local enhanced service funding for carer services in Scotland has been stopped in most Health Board areas, taking away incentive for practices to provide carer services.

Generally though, these approaches have led to a new focus within health settings on the needs of carers. They have encouraged local initiatives to better support carers, and drawn health and social care bodies into collaboration.

Earlier this year, the Scottish Parliament passed the Public Bodies (Joint Working) (Scotland) Act Bill. The integration of health and social care presents a major challenge to social services across health boards and local authorities. But it could be a real opportunity for joined-up working. This would particularly benefit carers, by ensuring they are recognised both by social care and health professionals. The 32 new partnerships will have different strategies. However, the partnerships are ideally placed to ensure identification and stronger partnerships between health and local authority services.

In January 2014, the Scottish government launched a consultation on carers' legislation. A report on the consultation, and future legislation, is expected later in 2014 and 2015. The consultation recognises that currently not enough carers are receiving carers' assessments. Health professionals need to identify carers and refer them for assessment, and this can work well when assessments are carried out by different bodies. For example, this was done by the Improving Cancer Journey initiative in Glasgow. Macmillan Cancer Support has responded to this consultation and we look forward to working to implement many of the proposed policies.



Health and social care partnerships formed by the Health and Social Care Integration Bill must integrate local government carer assessments with the Health Service as seamlessly as possible.

The recent Consultation on Carers by the Scottish government outlined some very positive possibilities to improve the lives of carers. While we await the outcomes and proposed legislation, Macmillan would like to see:

- the forthcoming legislation on carers continue to support the use of the third sector in carrying out carer's assessments
- positive action to improve the number of carers' assessments actually taking place.

Improving the cancer journey

In Glasgow in 2014, Macmillan launched our *Improving the cancer journey* programme to provide a holistic needs assessment to cover every newly diagnosed person with cancer in the city. This was in partnership with Glasgow Life, Glasgow City Council and the NHS. We are now able to offer carer assessments as part of the overall package of care and information. The ability to offer this service on the spot means we are picking up on carers' unmet needs.

Macmillan has a strong network of information and support staff in health and local community settings across Scotland. These services are used by carers and family members as well as by people with cancer.

Transforming care after treatment

Transforming care after treatment is a major component on the Scottish Cancer Taskforce workplan. It is a partnership between the Scottish government, Macmillan Cancer Support, NHS Scotland, the regional cancer networks, ADSW, COSLA, local authorities and the voluntary sector.

As part of a wider programme of reforms, one of the programme's aims is to support patients and health staff to move from the conventional medical model of care. Instead they will use a more holistic person-centred model, which signposts patients and carers to support resources currently available. This will be achieved by introducing a holistic needs assessment and a new questionnaire created by the multidisciplinary team.



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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/pro](https://www.macmillan.org.uk/pro) 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.

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