



TAKING THE BIG LEAP IN SCOTLAND

Sue, Macmillan Breast
Outreach Nurse

MACMILLAN
CANCER SUPPORT

Executive summary

Macmillan is the UK's leading source of cancer support, giving personal, one to one care and support to thousands of people every day. We help people make sense of their diagnosis, guide them through treatment, and provide physical, emotional and financial support in every aspect of life.

In Scotland we have a strong heritage of providing vital services for people with cancer – no matter their age, where they live, or their cancer diagnosis. From our network of Macmillan nurses to programmes implementing ground-breaking new models of care, we are providing the support that is needed now, innovating and driving change, so that together we will be able to meet the needs of the future.

Scotland will see unprecedented challenges in cancer care over the next ten years. Rates of cancer incidence and mortality are already higher than any other part of the UK, with the number of people living with cancer expected to grow a further 50% by 2030.

Faced with the additional challenges of a highly rural population, pockets of urban deprivation, and a system that is often confusing and disjointed, change is needed to ensure the best possible support for people throughout their cancer journey.

Our vision is that everyone diagnosed with cancer in Scotland should have the opportunity to access services tailored to their needs. And they should be able to get the physical, financial and emotional support they need to find their best way through.

We will do this through a number of key programmes of work:

The **Transforming Cancer Care** programme will join up support across acute, primary and community settings to ensure everyone with a new cancer diagnosis in Scotland has the opportunity to access the services they need.

Through **Macmillan Grants**, we will provide direct support to those in greatest financial need, helping to reduce money worries and allowing them to focus on what matters most.

And we will expand the **Macmillan Support Line** to ensure more people can reach us when they most need our help – for anything from clinical concerns to emotional support.

Our plans call for a significant level of investment over the next three years. We are seeking support for the first £2 million towards this – to help us take the big leap that is needed. This will help ensure that Macmillan can be there for those who need us, with the support that's right for them, from the moment of diagnosis.

Thank you.

An opportunity for change

Scotland faces an unprecedented challenge in cancer care. With higher cancer incidence and mortality rates than any other part of the UK, the current system is already stretched. It wasn't set up to support the ever-growing numbers of people living with the wide-ranging and long-lasting effects of cancer, but we have the opportunity to change this.

The challenge

There are approximately 220,000 people living with cancer in Scotland. As more people are being diagnosed and treatments improve, this figure is expected to increase dramatically over the next ten years – to an estimated 343,000 people living with cancer by 2030.

343,000
PEOPLE LIVING WITH
CANCER IN SCOTLAND
BY 2030

The situation in Scotland is challenging. Some 20% of the population live in remote or rural areas. For people affected by cancer in remote communities, there may be unequal access to health and social care support, due to long journey times to reach hospitals and fewer specialist services available to them.

Furthermore, there are significant pockets of deprivation, where the financial impact of cancer is felt most acutely. In 2015/16, over a million people in Scotland were living in relative poverty after paying their housing costs. In those most deprived areas, rates of cancer incidence are typically 30% to 50% higher than in the least deprived areas, and patients in deprived communities are up to 98% more likely to die from the illness.

The inequity in access to care and support

A cancer diagnosis can affect every aspect of life, bringing emotional, financial, practical and physical problems that can last long after treatments end. Having a clear, personalised care plan can make a huge difference; but right now, not everyone in Scotland has an assessment of their needs and a plan in place. With health and social care systems not joined up, they often fail to provide the all-round, tailored support people need.

Research has found that 76% of those who have had a cancer diagnosis in the previous 10 years – an estimated 100,000 people – had practical or personal care needs. Despite this, the Scottish Cancer Patient Experience Survey found that, among those who needed it, only 54% got enough care and support from health and social care professionals during treatment. The situation was worse after treatment, with only 45% of people saying they received enough care and support.

Furthermore, four in five people with cancer are affected financially – on average incurring costs of £570 a month because of their diagnosis. Almost a third also experience a significant loss of income, causing additional stress at a time when money worries should be the last thing on their minds.

Faced with a cancer diagnosis, people can also be overwhelmed by the amount of information out there. With concerns covering everything from clinical questions to guidance around money and work, they often simply don't know where to turn for information and emotional support.

Macmillan Cancer Support in Scotland

Macmillan has a strong track record of developing and delivering innovative services in Scotland – from our network of Macmillan nurses, to improving local access to information, to redesigning the delivery of coordinated health and social care.

Through the *Macmillan Libraries* programme, we have transformed how people access cancer information and support. By placing this support in libraries, right at the heart of communities rather than in more traditional healthcare settings, we are ensuring that quality information reaches people when and where people need it. In Glasgow, a comprehensive network of 16 weekly volunteer-led drop-in services, 19 information points and an outreach service means anyone affected by cancer is at most just one mile away from direct access to cancer information and support.

In 2013 we launched the £5 million *Transforming Care After Treatment* programme. This led to 25 pilot projects delivered jointly through NHS and local authority partnerships. Evidence shows that these deliver better care and support for people with cancer, whilst also freeing up staff like clinical nurse specialists to support those with the most complex needs.

We have also developed a ground-breaking programme in Glasgow – *Improving the Cancer Journey* – which ensures the all-round needs of people living with cancer are identified from the moment of diagnosis. Recognised as a model of best practice in the 2016 Scottish Government cancer plan, this programme has directly informed our plans to roll out similar support across Scotland.

Using our strong relationship with the Scottish Government, integrated joint boards, local authorities, cancer networks and other charities, we are able to develop new solutions and influence national policy, bringing about long term sustainable change. But we need the funding and support to help us deliver this.

'I was fortunate to be visited by you and given help and advice. It has been an upward struggle, but your expertise in knowing which direction to point me in has made it all worthwhile.'

'With your help, I can now face the future and my 'new life.'

Service user supported by
Macmillan in Dundee

Our vision for Scotland

We have a vision that everyone diagnosed with cancer in Scotland should be able to access the support they need from the moment of diagnosis. This means working across health and social care to put the right support in place, from the provision of care in hospital and the community, to financial help, to information and emotional support at the time and place people need it.

Creating lasting change

The cancer care system in Scotland needs to change. As the number of people living with cancer grows, we need to move away from a one-size-fits-all system and establish one that is tailored to meet all the needs of the person with cancer. This won't just be better for people with cancer, it will be better for the cancer care system.

Providing tailored support means NHS resources can be directed to where they're needed most. People will get support as soon as they need it instead of struggling with mounting problems that impact their physical and mental health, and they will be helped to access the support they need in their local community.

We are working towards creating a better cancer care system – one where everyone with cancer has access to the best clinical care possible, alongside the emotional, practical and financial support they need from the moment of diagnosis onwards. This support utilises the services available across all sectors, and ensures they are directed to where they can make the biggest difference for people living with cancer.

All-round support, from the moment of diagnosis

Cancer is not always life-threatening, but it is life-changing. Regardless of the diagnosis, life will never be the same again.

Our aim is that everyone living with cancer in Scotland should be able to get the physical, financial and emotional support they need to find their best way through.

We will roll out work to ensure the delivery of care is joined up across acute, primary and community settings, so that everyone with a cancer diagnosis can access services to meet their needs.

We will provide a range of integrated financial support, from direct grants to financial guidance, to help ease people's money worries and ensure they can concentrate on their treatment.

And we will expand how we offer vital information and support to people – whether on the phone, online, or in their community – to ensure they can get the support they need in the way that works for them.

How we'll do this

Over the next three years we will deliver a number of programmes of work aimed at ensuring people living with cancer can get the physical, financial and emotional support they need.

Transforming Cancer Care

We are currently working with the Scottish Government to plan the roll out of a ground-breaking programme across the country – one that will ensure everyone's needs are assessed at the point of diagnosis, and they have the opportunity to access services tailored to their needs.

This programme builds on work already developed in Scotland: *Improving the Cancer Journey (ICJ)* which focuses on putting in place all-round support for people from the moment of diagnosis; and *Transforming Care After Treatment* which provides more effective support for people after their treatment has ended. ICJ was recognised as a model of best practice in the Scottish Government's 2016 cancer strategy, and the government have pledged £9 million towards setting up similar services across Scotland.

Through Transforming Cancer Care, everyone newly diagnosed with cancer will be offered the opportunity to have a conversation with a Macmillan Link Worker to discuss their support needs and create a personalised care plan. They will complete an electronic Holistic Needs Assessment (eHNA) to establish any physical, emotional, social or practical problems they may have. A care plan will then be created to meet those needs, with the eHNA accessed by everyone involved in their care – from hospital, to their GP, to social care.

Macmillan Grants

Alongside the provision of hands on care and support, we will help people financially – from giving advice and support around money and work, to awarding direct grants to help people with the cost of cancer.

Macmillan Grants are one-off payments for people living with cancer who are in most financial need. They are given to help with additional costs such as travel to hospital or increased heating bills, which come at the very time people can least afford them.

In Scotland we award almost 5,000 grants totalling £2 million each year. These grants help improve the quality of life for people living with cancer, reducing worry and anxiety, and allowing them to focus on what matters most.

Macmillan Support Line

For many people, faced with a cancer diagnosis and overwhelmed by the amount of information to take in, they just need to talk to us – for help with clinical questions, practical or financial concerns, or emotional support.

The Macmillan Support Line plays a vital role in providing this information and support. Over the next three years we are significantly expanding the service, establishing Glasgow as a major hub to provide support across the UK.

As a first step, we are extending the support line to be available from 8am – 8pm, Monday to Sunday, 365 days a year. We are testing demand and building capacity, with the ambition that by 2021, people will be able to access the support they need 24/7.

Funding our vision

Our plans call for major investment in these three programmes. This map outlines the spread of Macmillan Professionals currently in funding and highlights where we plan to direct funding in each area to deliver this vital work.

Transforming Cancer Care

The map indicates the intended level of funding across Scotland*, based on population and level of need. We are now working with Health and Social Care Partnerships to plan how we will implement the programme in each region.

Macmillan Grants

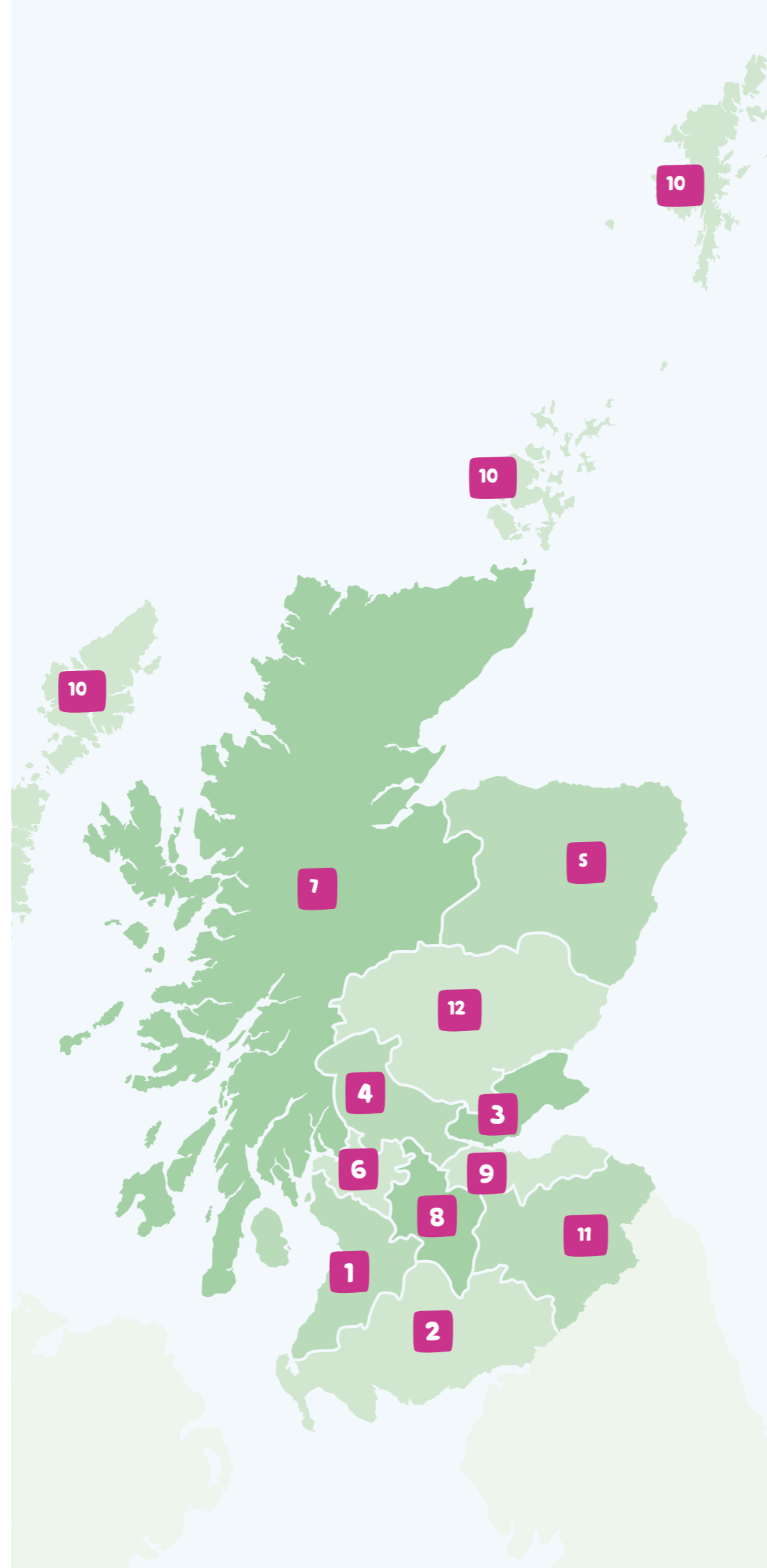
The map indicates the approximate value of Macmillan Grants we expect to make in each region over the next three years. This is a prediction based on historic grant giving; the total value of grants awarded will be in direct response to need.

Macmillan Support Line

As part of the expansion of our support line, we are seeking £1 million to fund 20 part-time Cancer Information and Support Advisers in Glasgow over three years. These new roles will be central to providing information and emotional support to people with cancer across the UK.

These programmes of work mark a huge ambition for Macmillan in Scotland. We are seeking the support of business leaders, philanthropic individuals and charitable trusts to raise £2 million towards this – to help us take the big leap and ensure Macmillan can be there for those who need us, with the support that's right for them, from the moment of diagnosis.

In the event of a surplus of funding for any area, either due to more funds being received than anticipated or a change in service plans, with the donor's agreement we would use this to fund other vital Macmillan services across Scotland.



1. Ayrshire & Arran

381,200 population
14,200 people living with cancer
11 Macmillan Professionals
Transforming Cancer Care: **£1.1m**
Macmillan Grants: **£480k**
Total: £1.58m

2. Dumfries & Galloway

154,200 population
6,200 people living with cancer
7 Macmillan Professionals
Transforming Cancer Care: **£430k**
Macmillan Grants: **£130k**
Total: £560k

3. Fife

380,500 population
13,000 people living with cancer
10 Macmillan Professionals
Transforming Cancer Care: **£1.1m**
Macmillan Grants: **£385k**
Total: £1.485m

4. Forth Valley

313,500 population
10,100 people living with cancer
6 Macmillan Professionals
Transforming Cancer Care: **£950k**
Macmillan Grants: **£285k**
Total: £1.235m

5. Grampian

610,400 population
18,700 people living with cancer
14 Macmillan Professionals
Transforming Cancer Care: **£1.8m**
Macmillan Grants: **£355k**
Total: £2.155m

6. Greater Glasgow & Clyde

1,182,200 population
38,100 people living with cancer
56 Macmillan Professionals
Transforming Cancer Care: **£3.66m**
Macmillan Grants: **£1.695m**
Total: £5.355m

Scotland-Wide

Macmillan Support Line: **£1m**

7. Highland

332,700 population
12,600 people living with cancer
13 Macmillan Professionals
Transforming Cancer Care: **£1m**
Macmillan Grants: **£260k**
Total: £1.26m

8. Lanarkshire

671,700 population
21,500 people living with cancer
11 Macmillan Professionals
Transforming Cancer Care: **£2m**
Macmillan Grants: **£1.01m**
Total: £3.01m

9. Lothian

904,000 population
30,000 people living with cancer
19 Macmillan Professionals
Transforming Cancer Care: **£2.8m**
Macmillan Grants: **£470k**
Total: £3.27m

10. Orkney, Shetland & Western Isles

75,200 population
2,600 people living with cancer
5 Macmillan Professionals
Transforming Cancer Care: **£900k**
Macmillan Grants: **£105k**
Total: £1.005m

11. Scottish Borders

116,800 population
4,900 people living with cancer
8 Macmillan Professionals
Transforming Cancer Care: **£320k**
Macmillan Grants: **£90k**
Total: £410k

12. Tayside

428,500 population
14,600 people living with cancer
18 Macmillan Professionals
Transforming Cancer Care: **£1m**
Macmillan Grants: **£375k**
Total: £1.375m

**The intended level of funding for each region is approximate, and is subject to discussion and agreement with partner organisations.*

Transforming support across Scotland

Our plans aim to transform the provision of care for people with cancer in Scotland. From more joined up care to providing financial help and emotional support, this will be better for people with cancer, and it will be better for the health and social care system.

Better for people living with cancer

Our aim is that every single person in Scotland with a new cancer diagnosis will have the opportunity to access services to meet their needs. Through a supported conversation about their emotional, financial, practical or physical concerns, we will help to ensure they can access the right support for them, at the time they need it.

We will address inequalities by ensuring support is targeted to those who need it most, and we will make sure it is accessible to those who live in the most socially deprived areas of Scotland.

We know the difference this can make from our experience of delivering *Improving the Cancer Journey (ICJ)* in Glasgow.

An evaluation by Edinburgh Napier University (below) highlighted the significant impact of this programme, which has directly informed the development of Transforming Cancer Care.

By ensuring that alongside high-quality care and support, people can get the financial and emotional support they need, we will help to ensure they are able to find their best way through.

Across Scotland, people will have better access to quality care from the moment of diagnosis, with the information and support they need in all in all aspects of their life, and will be better able to live life as fully as they can.

Better for the health and social care system

This will also be better for the health and social care system. Support will be better integrated across health, social care, and the third sector, enabling the system to meet the needs of people living with cancer more efficiently and more cost-effectively.

With support more targeted, it will make better use of valuable NHS resources, and increase the capacity of the system to meet people's wide-ranging needs.

This work will truly transform the pathway for everyone in Scotland to one that is better integrated and better able to meet the needs of people living with cancer, from the moment of diagnosis. And it has the potential to influence the delivery of joined up health and social care for other long-term conditions across Scotland.

We would love to share our plans with you and explore how you might be able to support our work.

For more information, please call 020 7840 4895 or email philanthropyenquiries@macmillan.org.uk

The impact of ICJ in Glasgow

So far, ICJ has supported over 5,000 people with cancer and handled 18,000 concerns ranging from money and housing worries to fatigue and getting around.

An evaluation by Edinburgh Napier University found that for most people, the programme reduces distress to a manageable level for them to be able to cope and help themselves. 93% report feeling less isolated, with 86% saying they feel less stressed, and 79% saying they feel more in control.

Evidence also indicates that ICJ frees up time for hospital staff, allowing nurses to concentrate on nursing and helping to ensure the best use of valuable NHS resources.

ICJ demonstrates how an integrated approach to delivering personalised support across health and social care can significantly improve patients' quality of life, access to support networks, and confidence in managing their own health.



9 out of 10 people said they feel less isolated

James was diagnosed with bowel cancer just after being made redundant from his job as a cleaner. He was living in a bedsit and sharing a bathroom with strangers when his nurse referred him to ICJ.

'When you have bowel cancer you really need to have your own bathroom. After ICJ got in touch with me they got me a flat of my own. If it wasn't for them I think I'd still be in the bedsit. ICJ also helped me claim benefits. They just sorted that all out for me.

'Tracey from the service calls me regularly to see how I'm doing and ask if I need anything. Just knowing she's there has taken away so much of my worry and stress.'



Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland

MACMILLAN
CANCER SUPPORT
RIGHT THERE WITH YOU