



Care and support
through terminal illness

2022 Local Government Elections Manifesto

Scotland needs Compassionate Communities



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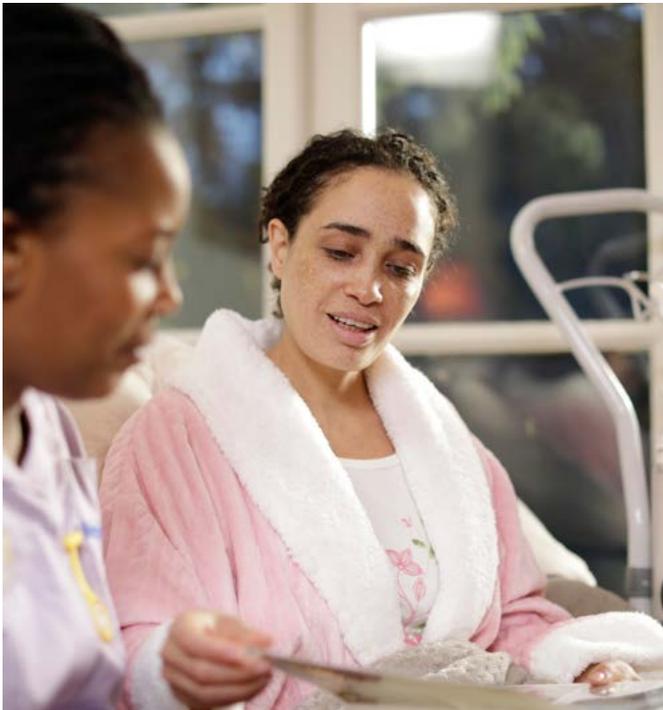
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About Marie Curie

Marie Curie is here for anyone living with a terminal illness, their families and carers. We offer care, guidance and support to help people to live as well as possible in the time they have left.



Layton Thompson/Marie Curie

In Scotland*

In 2020-21, over **63,000** people died**.

Over **56,700** of these people had a palliative care need.

During the pandemic, there was a **40% increase** in deaths at home.

Marie Curie in Scotland

We cared for **9,038** people with a terminal illness in 2020/21.

*In the NHS boards covered by this region.

**Source: nrscotland.gov.uk

Our fundraising, care and support services in Scotland

2 hospices

6 active research projects

31 local authorities supported by our nursing service

32 local authorities, and almost 100,000 people, used our Information and Support service

32 shops

77 fundraising groups

166 households supported by our volunteer Helper service

1,539 volunteers

1/3 of care and support is paid for by gifts in Wills

In Scotland by 2040:

62,000+ people will be dying with palliative care needs each year

co-morbidities will have increased by **80%**

the greatest increase in palliative care need will be in **over 85s**

2/3s of all deaths will happen in community settings.

Our vision

Every local community in Scotland should be a place where dying, death and bereavement is talked about openly, where everyone can plan and discuss their end of life care and wishes, and access physical, emotional and spiritual palliative care and support relevant to their needs.

Our ask of Local Government

Marie Curie is calling for all Local Government Election candidates to support dying, death and bereavement in their areas through committing to:

- **Leading and supporting their areas to embed [Compassionate Communities](#)¹; harnessing the resources, compassion and dedication of local people to support everyone affected by dying, death and bereavement to access the physical, emotional and spiritual support they need to live as well as possible**
- **Supporting the other recommendations for Councils and Integration Authorities in this Manifesto, to ensure everyone has the best possible end of life experience which reflects what is most important to them**

A whole-system, public health approach to supporting people affected by dying, death and bereavement should be embedded in local systems, bringing together all palliative and end of life care service providers, including the third sector, and leveraging community resources to deliver support which reflects people's palliative care needs.

What is palliative and end of life care?

Palliative care supports a terminally person with any advanced, progressive illness(es) to have a good quality of life, being as well and active as possible in the time they have left. This includes physical support to manage pain and symptoms, emotional, spiritual and psychological care, as well as support from family and friends. A person can receive palliative care at every stage of their illness, and it can be delivered in different care settings such as a person's own home, care home, hospital or hospice, by generalist/specialist health and social professionals such as GPs, District Nurses and social care teams.

What is a Compassionate Community?

A social movement which empowers local people to help transform attitudes and practice around dying, death and bereavement. Alongside existing formal services in the community, local people support those with deteriorating health, their families and carers to help them to live as well as possible, as demonstrated by [Compassionate Inverclyde](#).² Compassionate Communities use a local network of volunteers, fundraisers, befrienders, companions, community cafes, and compassionate local businesses and schools to help those affected by dying, death and bereavement to live well and access the physical, emotional and spiritual support they need.³

How to get involved?

Some local areas are already involved to some extent in Compassionate Communities, but this must be supported fully by every Local Authority across Scotland. Good Life, Good Death, Good Grief is an organisation which facilitates a [Scottish Compassionate Communities Network](#) to share learnings, experiences and ideas alongside a [Scottish Compassionate Communities Toolkit](#) to support implementation.

Covid-19 has reinvigorated community appetite to be part of local initiatives, such as Marie Curie's [volunteer-led befriending service](#), which make a difference to the lives of the most vulnerable. Local

Authorities must harness the compassion and dedication of communities more deliberately and efficiently than is currently the case.

Dying, death and bereavement in Scotland: what does the future hold?

In Scotland in 2020-21, more than 62,000 people died¹. Around 90% of those (56,000) had a palliative care need in the final years, months, weeks, days and hours of their life. Scotland's ageing population also means more people will be dying in the years to come.

Marie Curie research projects that by 2040:

Up to **10,000 more** people will be dying every year with palliative care needs

Co-morbidities (more than one terminal condition) will have **increased by 80%**

The **greatest increase** in palliative care need will be in **over 85s**

Nearly two-thirds of all Scottish deaths will take place in community settings by 2040, in people's own homes, care homes or hospices

Covid-19 has provided insight into what increased demand for palliative support in the community could look like, with over 6,000 more Scottish deaths at home in 2020 than in previous years. This trend of increased deaths at home has continued even as waves of Covid-19 have dropped, suggesting this could carry on into the short and medium term, and highlighting the need for well-equipped services and workforces to manage demand.

“There has definitely been a shift towards palliative and end of life care in the community, and this has been further enhanced due to the implications of the COVID pandemic.”

Marie Curie Nurse

Being identified for and accessing palliative care

One of the biggest challenges facing people who are diagnosed with a terminal illness is being able to access the care and support they need. **Many miss out on some or all of this care**, and never have the chance to discuss their preferences for end of life care (including spiritual and social) with health and social care professionals or their families, known as Anticipatory Care Planning (ACP). The need for palliative care to be integrated with health and social care systems has never been greater. **Marie Curie led research has found that only 47% of people with organ failure had a Key Information Summary (KIS) which details core information about a patient's support needs, compared with 80% of people living with cancer** ⁴. There was also significant variation in the completion of KISs by Health Boards.

Integration authorities must champion the completion and implementation of a KIS so terminally ill people get the right care and support throughout their illness

“Until I had personally had to be involved in meetings to discuss care for my gran, I had no idea that there were so many requirements, so many forms or that the waiting times for assessments could be so long. I think that if people had a better understanding of what might happen then they would take steps to prepare and make sure their loved ones won't be faced with worry over what is the right thing to do.”

Marie Curie staff member

Role of Local Government in palliative and end of life care

Strengthening Health and Social Care Integration

Health and social care are still less integrated than was intended when the Public Bodies Act was passed. **Marie Curie is the largest third sector provider of palliative care services for adults in Scotland.** The third sector plays a key role in integrated services, but is not treated as an equal partner, and is often not included in early conversations with Integration Authorities regarding the strategic planning and commissioning of palliative care services, despite having extensive expertise, knowledge and skills.

The third sector must be included as voting members of all Integration Authorities in Scotland, and included in the strategic planning of palliative care services

Commissioning packages of care has also become incredibly varied by many Integrated Joint Boards (IJB). This presents significant challenges as care and support needs differ across regions based on population and urban/rural locality. There is a recognition and understanding that the third sector and statutory sources will both have fewer financial resources in the future, highlighting a need for greater collaborative, co-produced working and innovation with all key stakeholders. This will be even more crucial following the impact of Covid-19.

IJBs must take a strategic, whole-system approach to developing and commissioning palliative care services, which are focused on outcomes and needs of terminally ill people in each Local Authority area

The Scottish Government's previous [Strategic Framework for Action on Palliative Care 2016-2021](#) stated that by 2021, 'everyone who needs palliative care will have access to it'. Unfortunately, despite making some progress, Government has fallen short of this ambition. Scottish Government has committed to a new national strategy for palliative and end of life care, and a National Clinical Lead to progress a clear vision for palliative care in all settings.

We urge Integration Authorities to set out how they will support this in future, including a clear delivery plan for palliative care in all IJB/HSCP strategies

Community Councils and Community Planning Partnerships

Community Councils (CCs) and Community Planning Partnerships (CPPs) play a pivotal role in helping to make their areas the best possible places to live. Collaboratively, their networks could be a vital resource to Local Authorities by helping to identify people affected by dying, death and bereavement who could benefit from support. They could also play a role in championing Compassionate Community initiatives.

Local Authorities should support all Community Councils to progress a Local Development Plan which is specific to each local population's palliative care needs, and empowers communities to lead delivery of support with all service providers

Local Authorities, Community Councils (and other partners) should support CPPs to produce Local Outcome Implementation Plans and Locality Plans which embodies a Compassionate Community approach

Social Care

Social care is an integral part of the care terminally ill people receive, helping them to live as well as possible until their death. Terminally ill people are increasingly dependent on social care as they approach the end of their lives, thus services must be able to be flexible when their requirements change. But too often, the social care needs of terminally ill people are not being met, placing the burden on families. When a family reaches crisis point, this often leads to an avoidable hospital admission. We know the National Care Service will mark a shift in the way social care is planned, commissioned and delivered in Scotland. Once these processes have been finalised:

Local Authorities must take an evidence-based approach to identifying the palliative and end of life care needs of their population, including social care needs, with sufficient resources to ensure services can respond when terminally ill people's needs change



Philip Hardman/Marie Curie

Housing and Homelessness

Housing

Many terminally ill people, including those supported by Marie Curie, prefer to receive palliative care and die at home where that is possible. **In 2020-21, over 90% of the last six months of life of those who died was spent in community settings** ⁶. But terminally ill people often face significant barriers getting the equipment and home adaptations they need, particularly when transitioning between care settings, such as hospital to home. This can often lead to the person's discharge being delayed, which means they may not get to die in their preferred place of choice.

Local Authorities should reform home adaptation processes with a fast-track option for terminally ill people through the use of a BASRiS form, to ensure they can live as independently as possible in the time they have left

Homelessness

Over 200 people die in Scotland each year while homeless, with an average age of just 39 for women and 43 for men ⁷. Despite people experiencing homelessness having significantly worse health than the general population,, higher death rates and more complex health needs, they also face significant barriers accessing palliative and end of life care and it is unknown what, if any, palliative care support they receive. [Dying in the Cold; Being Homeless at the End of Life](#) co-authored by Marie Curie and Dr Joy Rafferty, Strathcarron Hospice, makes recommendations to support better access to and delivery of palliative support for people experiencing homelessness.

Every Local Authority should have a dedicated homelessness lead and integrated homelessness strategy with HSCPs based on local population needs, including palliative and end of life support, and adopting a parallel planning approach ⁸

What is parallel planning?

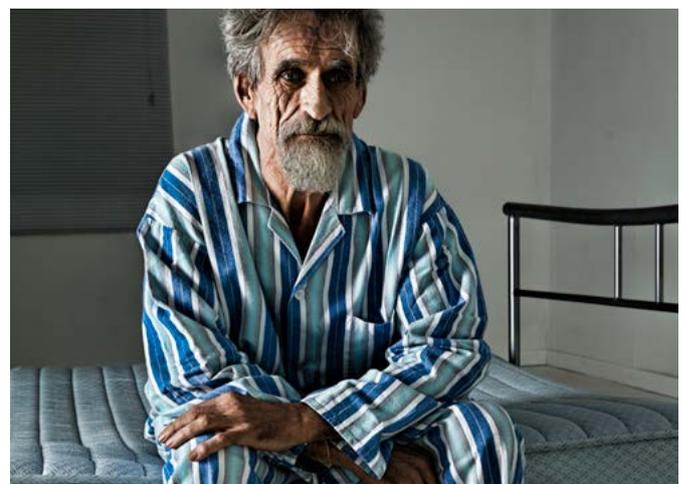
A parallel planning approach involves hoping for the best, but planning for the worst. where palliative care and anticipatory care planning are carried out alongside plans for rehabilitation and recovery, where appropriate ⁹.

Health Inequalities and Inequities

Covid-19 has had a significant impact on poverty, deprivation and exclusion, deepening existing health inequalities and inequities. Data has shown that deaths from Covid-19 have been significantly higher in areas of socio-economic deprivation in Scotland; over double in the most deprived areas compared to the least deprived.

We know from existing evidence that terminally ill people affected by this cycle of poverty, deprivation and exclusion, as well as wider health inequalities, have historically faced multiple barriers in accessing and engaging with palliative care support in their communities. These barriers range from a lack of care options and health literacy, to barriers because of race, gender, faith, age, sexuality and location, amongst others. More must be done by Local Authorities to tackle such inequalities and inequities across Scotland by taking a whole-system, public health approach.

Seldom heard groups must be involved in Integration Authorities' membership, structures and design of palliative care support and community networks from the beginning, to ensure equal access to palliative care for everyone, which reflects individual needs¹⁰



Grief and Bereavement

People experience grief and bereavement at different stages and in different ways. In some cases, grief begins before a person has died and it often continues for a long time afterwards. Pandemic restrictions on visits to care homes, hospitals and hospices resulted in a lonelier end of life experience for many. It has caused profound damage to bereaved families and carers, as well as health and social care professionals. Preliminary findings of Marie Curie funded research into the experiences of bereaved carers during the second Covid-19 wave (October 2020–March 2021) have shown that, while direct care has remained good, it has been more challenging to provide, and family carers have suffered. More extensive, tailored support will be needed for the bereaved experiencing complicated grief, including health and social care staff.

Local Authorities must support the Bereavement Charter for Scotland which champions everyone's right to access the support they need following a bereavement by applying to adopt the Bereavement Charter Mark (BCM) (**The BCM indicates organisations

which have adopted the principles of the Charter).

Funeral Poverty

Everyone should have a dignified and respectful funeral, which does not force families into harmful debt; around 1 in 10 families in Scotland cannot afford to pay for a funeral they are responsible for¹¹, which can also affect their grief. The Scottish Government's Funeral Support Payment to help with funeral costs is welcome, but burial and cremation fees are still a postcode lottery in Scotland; people living in one Council area may pay over £2,000 more than someone in another Council area for burial interment and lair¹². Local Authorities must ensure that burial and cremation costs are fair and kept as reasonable as possible.

Scottish Councils should set burial and cremation costs to broader strategies aimed at reducing poverty, to ensure bereaved people do not experience additional financial and emotional burdens following a death

Support for family carers

The role of family carers in a person's palliative and end of life care is crucial in helping terminally ill people get the day-to-day support they need for a good quality of life. But support for family carers themselves is often overlooked and needs to be more greatly recognised¹³. This has been exacerbated by Covid-19, as it has been estimated that an additional 400,000 people took on unpaid caring roles during the first Covid-19 lockdown due to health and social care restrictions¹⁴, and many are completely exhausted from these pressures.

All Local Authorities must ensure that carers are identified by health and social care professionals and referred for support where appropriate, including for an Adult Carer Support Plan (ACSP) or Young Carers Statement (YCS). For those caring for someone with a terminal illness it will be important that this support is prioritised and fast-tracked to avoid a breakdown in care¹⁵.



Philip Hardman/Marie Curie

Marie Curie policy asks for the Scottish Local Government Election 2022

Compassionate Communities

Local Authorities must lead and support their areas to embed [Compassionate Communities](#) ¹⁶; empowering local people to support everyone affected by dying, death and bereavement to access the support they need to live as well as possible.

Strengthening Health and Social Care Integration

- Leading and supporting their areas to embed [Compassionate Communities](#) ¹⁷; harnessing the resources, compassion and dedication of local people to support everyone affected by dying, death and bereavement to access the physical, emotional and spiritual support they need to live as well as possible
- The third sector must be included as voting members of all Integration Authorities in Scotland, and included in the strategic planning of palliative care services
- IJBs must take a strategic, whole-system approach to developing and commissioning palliative care services, which are focused on outcomes and needs of terminally ill people in each Local Authority area
- We urge Integration Authorities to set out how they will support the Scottish Government's national palliative care strategy in future, including a clear delivery plan for palliative care in all IJB/HSCP strategies

Community Councils and Community Planning Partnerships

- Local Authorities should support all Community Councils to progress a Local Development Plan which is specific to each local population's palliative care needs, empowers communities to lead delivery with all service providers
- Local Authorities, Community Councils (and other partners) should support

Community Planning Partnerships to produce Local Outcome Implementation Plans and Locality Plans which embodies a Compassionate Community approach

Social Care

- Local Authorities must take an evidence-based approach to identifying palliative and end of life care, including social care, needs of each Local Authority population, with sufficient resources to ensure services can respond when terminally ill people's needs change

Housing and Homelessness

- Local Authorities should reform installation processes with a fast-track option for terminally ill people through the use of a BASRiS form to ensure they can live as independently as possible in the time they have left
- Every Local Authority should have a dedicated homelessness lead and integrated homelessness strategy with HSCPs based on local population needs, including palliative and end of life support, and adopting a parallel planning approach ¹⁸

Health Inequalities

Seldom heard groups must be involved in Integration Authorities' membership, structures and design of palliative care support and community networks from the beginning, to ensure equal access to palliative care for everyone, which reflects individual needs ¹⁹

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