Marie Curie Scotland response to the Health and Social Care Committee Inquiry: Healthcare in remote and rural areas

The forgotten inequity: palliative care access and delivery in rural, remote and island communities.

20th October 2023

1. Are there any immediate issues unique to remote and rural communities which the National Centre will need to focus on to improve primary and secondary care in these areas?

a) The National Centre is an opportunity which must be taken to focus on accessibility and delivery of palliative and end of life care in rural, remote and island communities.

b) In 2022-23, there were almost 63,000 deaths registered in Scotland[1]; around 90% of those (56,700) had a palliative care need.

c) Palliative care offers physical, emotional, psychological and practical support to people with any illness they're likely to die from. This includes Alzheimer's (or another form of dementia), heart, liver or kidney disease, motor neurone disease and advanced cancer.

d) Palliative support also includes symptom management, and can be offered at any point after a terminal diagnosis. Someone can live for years, months, weeks or days with a terminal illness following their diagnosis. End of life care is part of palliative care. It is treatment, care and support for people who are thought to be in the last

[1] NRS Vital Events Reference Table 2022-23

year of life, though some people may receive end of life care for longer, or only in their last weeks or days.

e) Palliative care can be provided in different settings, including in hospital, a hospice, care or nursing homes and a person's own home. Palliative care aims to support a person to have a good quality of life – this includes being as well and active as possible in the time they have left. It can involve:

- managing physical symptoms such as pain
- emotional, spiritual and psychological support
- social care, including help with things like washing, dressing or eating
- physical, emotional, spiritual and financial support for family and friends

f) Scotland has an ageing population, and particularly high elderly populations in rural, remote and island communities, where palliative care needs vary. Marie Curie research has found that by 2040, the biggest increase in palliative care demand will be in over 85s[2], meaning a large proportion of future palliative care need is likely to be in rural, remote and island communities.

g) In 2022-23, deaths of people aged 75 and over in Scotland accounted for almost 65% of all deaths and resulted in 200,000 people experiencing bereavement. Those 85+ accounted for a third (34%) of deaths,[3] resulting in 106,000 people experiencing bereavement.

h) A large proportion of these deaths and bereavements will have taken place in rural, remote and island communities but with varying access to all of the palliative support they needed for an end of life experience which reflects what's most important to them.

i) Our research has also found that people dying with multi-morbidities (more than one terminal condition) will have increased by over 80% in this time, meaning people will be dying with more complex palliative care needs.

j) While rural elderly populations are increasing, there is lower demand and accessibility to specialist healthcare, including palliative and end of life care, and terminally ill patients living in rural and remote areas are at significant risk of being hidden and forgotten[4].

k) **The challenges faced by rural, remote and island communities in accessing and delivering palliative care highlight an identified inequity, and can be summarised by the four As below. These should be central to the National Centre's short, medium and long term priorities**:

l) **Availability**; of resources for palliative and end of life care providers, including specialist palliative care teams, social care workforce and carers, to meet the needs of terminally ill people. Challenges with resources include workforce

[2] Finucane, A.M., Bone, A.E., Evans, C.J. et al. The impact of population ageing on end-of-life care in Scotland: projections of place of death and recommendations for future service provision. BMC Palliative Care 18, 112 (2019)

[3] NRS Vital Events References Tables 2022-23

[4] https://spcare.bmj.com/content/3/1/129

recruitment and retention (which will be explored further in the response), and equipment and technology in care homes, hospices, hospitals and at home.

m) Rural, remote and island communities are also usually more accepting of death, as it is interpreted as a social event[5], but there is greater understanding needed of rural attitudes, cultures and traditions, and role of community networks in supporting end of life experience.

n) **Accessibility**; challenges terminally ill people, their families and carers face accessing palliative and end of life care, including access to medicines and pharmacy support. Intersectional transport issues are at the heart of this, including poor road conditions, lack of public transport, lack of volunteer drivers and lack of accessible vehicles. This can leave people reliant on expensive private transport.

o) Geographic accessibility is a significant determinant on how easily terminally ill people, families and carers can physically reach a palliative care provider's location.

p) Research has shown geographical access to inpatient palliative care is associated with where people die, and patients living more than 10 minutes from inpatient care are less likely to die there, irrespective of that is their wish[6].

q) More broadly, people living in rural areas are less likely to live within 15 minutes' drive of key public services, particularly those in remote rural areas[7].

r) More people (including older people) in rural areas will be dying at home, whether or not that is their preferred place of care and death because they cannot reach different care settings such as care homes, hospital or hospices. This places increased demand on community palliative care providers, including the social care workforce, and carers who already face significant challenges delivering palliative care in rural and remote settings.

s) **Accommodation;** how palliative care providers meet terminally ill people's preferences and needs. Of greatest concern are existing out of hours of operations in rural and remote areas, e.g. how phone calls are handled, by whom and how they are actioned, and a patient's ability to receive palliative care without prior appointments (including emergency admissions).

t) Accommodation also relates to the condition of terminally ill people's own homes, and challenges with limited accessible housing, and/or ensuring homes are fit for purpose to receive palliative and end of life care, and to die there, if that is their wish.

u) **Affordability**; of living in rural and remote areas. The "rural premium" means those living in rural and remote areas face significantly higher costs in housing, energy

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[5] Are rural and remote patients, families and caregivers needs in life-limiting illness different from those of urban dwellers? A narrative synthesis of the evidence Author: Kirby, Sue ; Barlow, Veronica ; Saurman, Emily ; Lyle, David ; Passey, Megan ; Currow, David

[6] Chukwusa, Emeka; Verne, Julia ; Polato, Giovanna ; Taylor, Ros ; J Higginson, Irene ; Gao, Wei *Urban and rural differences in geographical accessibility to inpatient palliative and end of life care facilities and place of death: a national population-based study in England*

[7] Evidence from NHS Highland and University Highlands and Islands to UK Government Inquiry into Cost of Living in Rural Communities 2023

food, and transport among others. This is before additional costs associated with terminal illness which Marie Curie projects costs an individual between £12-16,000 per year.

v) Affordability also centres around sustainability of palliative care funding in rural and remote areas. Urban centric models are usually transferred, ineffectively, to rural and remote areas because they do not reflect rural and remote challenges as above.

2. Are there any issues which the Centre will be unable to address, which may require further policy action from Government?

a) There are several cross-cutting issues which Marie Curie strongly believes must be considered as part of every person's end of life experience, and urges the Committee to consider them alongside the Centre's focus, as they will require further action from Scottish, Local and UK Governments.

b) **Poverty.** Marie Curie and Loughborough research has found that 8,200 people die in poverty at the end of life every year in Scotland, equating to an average of one in four working age people, and one in eight pensioners[8]. Two in three people living with a terminal illness are reliant on benefits as a main, or sole, source of income.

c) This financial burden also falls on families and carers, and the **excess costs of living with a terminal illness(es), including higher energy bills and housing adaptations, are estimated to cost a household between £12,000- £16,000.**

d) The double burden of income loss caused by having to reduce working hours, or giving up work completely, and additional costs associated with terminal illness, often leaves people struggling to make ends meet.

e) **When coupled with the "rural premium" described in point 1U, it puts terminally ill people, their families and carers in rural, remote and island communities at particular risk of severe poverty.**

f) **Energy.** In remote rural areas, 33% of households are in extreme fuel poverty compared to 12% in accessible rural areas and 11% in the rest of Scotland[9].

g) Rural areas also have less energy efficient housing than the rest of Scotland, with a median energy efficient rating of 53, compared to 61 in accessible rural areas, and 68 in the rest of Scotland[10].

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[8] Marie Curie Dying in Poverty in Scotland https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/h420-dying-in-poverty-scotland-4th-pp.pdf

[9] Evidence from NHS Highland and University Highlands and Islands to UK Government Inquiry into Cost of Living in Rural Communities 2023

[10] Evidence from NHS Highland and University Highlands and Islands to UK Government Inquiry into Cost of Living in Rural Communities 2023

h) 84% of Marie Curie Hospice Care at Home staff tell us that they have cared for patients struggling with energy costs, particularly those in rural, remote and island communities.

i) In a poll Marie Curie previously commissioned of the Scottish public, 94% of respondents said they were concerned about family or friends who are terminally ill being able to keep their home warm over autumn and winter. This is particularly acute in rural, remote and island communities where temperatures are colder, for longer.

j) Many terminal conditions can cause poor circulation and limit mobility, forcing people to have their heating on at a high level. This is often coupled with further costs from medical equipment such as nebulisers and ventilators and extra utilities, as well as using washing and tumble drying machines multiple times a day.

k) **Housing.** From 2021 to 2022, people who were dying spent around 90% of the last six months of their lives at home[11], and further Marie Curie research has shown that two thirds of people will be dying at home, in a care home or hospice by 2040.

l) However, demand for properties in rural, remote and island communities, let alone accessible properties and home adaptations currently outweighs supply [12] .This generates further implications for bereaved families in remote and rural areas facing eviction from their property after the terminally ill person has died.

m) Long waiting periods for adaptations are also common for people living with terminal illness, and many who are living in unsuitable accommodation would prefer for their current home to be adapted to suit their needs, but not all existing grants cover these costs and even subsidised adaptations can prove too costly at the end of life: **"A man who is an amputee was told by an OT that he would be unable to get adaptations to his home in the first instance so should be putting his name onto the housing list for sheltered accommodation. Whilst this was happening he had then gone back into hospital."-** Marie Curie Hospice Care at Home Team.

n) **Transport.** Rural households are also more likely to spend over £100 per month on fuel for their cars than households in the rest of Scotland[13]. Terminally ill people can have multiple appointments each week, and transport issues such poor road conditions, lack of public transport, lack of volunteer drivers and lack of accessible vehicles can leave people reliant on expensive private transport.

o) **Unpaid Care.** Carers have a crucial role in helping terminally ill people get the day-to-day support they need for a good quality of life. It would be difficult for anyone to die at home without a live in carer, particularly in rural, remote and island communities because of challenges in accessing specialist and/or generalist palliative support.

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[11] Public Health Scotland: percentage of last six months of life spent in community settings 2021-22

[12] https://www.heraldscotland.com/business_hq/23342555.highlands-islands-housing-crisis-hampering-economic-growth/

[13] Evidence from NHS Highland and University Highlands and Islands to UK Government Inquiry into Cost of Living in Rural Communities 2023

p) Many carers also do not self-identify as carers or get picked up by formal services and therefore miss out on support, and benefits, they may be eligible for. This is more acute in rural, remote and island communities given unique challenges with locality, and access to respite and self-care. Carers also experience increased emotional burdens and care expectation including management of medications, isolation and loneliness, and grief.

q) Despite these challenges, some evidence suggests rural settings enable care-giving to be personalised and culturally appropriate to rural, remote and island communities[14], although further research is needed to better understand these experiences, and how they can be grown and scaled where appropriate.

r) Marie Curie urges the Committee to consider these issues alongside the focus of the Centre, as they all directly impact a person's end of life experience with action required from Scottish, Local and UK Governments.

3. What would you like to see in the Scottish Government's forthcoming Remote and Rural workforce Strategy?

"We had a very prompt response from Marie Curie, and action was taken as well as just calling. This prevented carer fatigue at a difficult time of the patient's illness.

"Marie Curie providing support made us feel like we had a team again to support our patient". Dr Celine O'Neill, GP at Coll Medical Practice.

a) **In order to achieve person-centred palliative care, the strategy must commit to a whole-system, public health approach with service integration and partnership working at its heart**. This is vital to ensuring people affected by dying, death and bereavement in rural, remote and island communities have an end of life experience which reflects what is most important to them.

b) Yet palliative and end of life care needs are currently not as person-centred in rural, remote and island communities due to workforce pressures and lack of access to palliative support. Instead, terminally ill people's needs are shaped by services which are available, which might not include all of the support they need.

c) The third sector plays a key role in integrated services but is not seen as an equal partner and is often not included in early conversations with existing Integration Authorities regarding the strategic planning and commissioning of palliative care services. This has often been Marie Curie's experience of supporting the development of palliative care services in various Health and Social Care Partnership areas.

[14] Living, loving, dying: Insights into rural compassion Author: Marsh, Pauline; Thompson, Stephanie ; Mond, Jonathan

d) Marie Curie is the largest third sector provider of palliative care services for adults in Scotland, as well as being the leading charitable funder of palliative and end of life care research. But much of the third sector engagement with existing IJBs at Board level is channelled through the Third Sector Interfaces (TSIs), which act as the official representatives of the sector on those Boards. However, TSIs are not always effective in being able to directly represent the whole sector.

e) Marie Curie's engagement with TSIs has been minimal. In our experience, many, although not all, TSIs believe that national charities such Marie Curie are either not present locally or able to represent themselves to IJBs, thus do not actively engage us in consultation work or activity with existing IJBs.

f) We believe that new ways of engaging with the third sector should be explored as part of the strategy, so that the full breadth of the sector's experience and knowledge can be utilised to support rural, remote and island palliative care and generalist workforces.

g) A "consultancy approach" should be considered as part of the strategy, which identifies all multi-disciplinary workforces responsible for palliative care delivery, including specialist palliative care, GPs, social care, out of hours and community pharmacists.

h) Bringing together multi-disciplinary workforces, including the expertise and skills of Marie Curie hospice care at home teams, would form a peripatetic model of expert care delivery specific to local areas which works in partnership with local teams and communities, enabling terminally ill people in island, rural and remote areas to die at home.

i) This model could also act as an early warning sign for identification of wider elements of end of life experience, such as financial hardship, fuel poverty and carer burnout. It would also provide an opportunity to signpost appropriate support, including **Marie Curie's Information & Support services**, which includes energy advisors, and practical support for terminally ill people, carers and health and social care professionals, as well as bereavement support.

j) Social care is also an integral part of palliative and end of life care helping terminally ill people to live as well as possible right up until their death. This includes being able to die in their place of choice, when possible, which is often at home or in a community setting.

k) Those living with a terminal condition are increasingly dependent on social care, particularly approaching the end of their lives, alongside primary care and palliative care services.

l) Yet, social care staff are more likely not to have formal training in palliative and end of life care. Palliative care training must be incorporated into the strategy's implementation for all health and social care workforces, to ensure they are

empowered and fully equipped to support terminally ill people's needs. This would also support workforce recruitment and retention which continues to be a considerable issue in rural, remote and island communities especially.

m) Palliative care training could be facilitated through an ECHO model, which is a collaborative (and multi-disciplinary) medical education model that aims to build workforce capacity in rural, remote and island communities[15]. There are already several active ECHOs in Scotland, which could be grown and scaled to support the unique needs of people affected by dying, death and bereavement in rural, remote and island communities.

n) Rural and remote areas also typically experience higher emergency admissions because community and smaller hospitals, as well as out of hours services, are not fully equipped to manage terminally ill patients' needs.

o) To reduce pressures on these workforces, the strategy must consider alternative ways to support terminally ill people, carers and families in rural, remote and island communities at home.

p) This should include a palliative care advice and information line, which would ensure there is access to high quality, expert palliative care advice which is widely known and accessible to all when needed most. It would require a partnership approach between third sector providers of palliative care, NHS (including NHS 24), Integration Authorities and Scottish Government.

q) Community Pharmacists are also central to implementing an integrated and partnership approach to dying, death and bereavement, especially in rural, remote and island communities where there are acute challenges with access to palliative support.

r) Royal Pharmaceutical Society and Marie Curie have developed **professional Standards** for palliative and end-of-life care in community pharmacy, where pharmacies sign up to the quality improvement Standards that provide a framework to help them continuously improve their end of life and bereavement care for terminally ill patients, their families and carers.

s) **"I wish we could have had a meeting with the pharmacist at the time of diagnosis so we were more prepared for all the changes in medicines and different side effects"- patient feedback to the Standards.**

t) The role of digital and telehealth also has a central role in the Scottish Government's remote and rural workforce strategy, through reducing workforce pressures and improving access to palliative care, regardless of location, while also supporting a minimum standard of care.

u) However, digital exclusion must be considered as part of this approach, particularly related to user confidence of digital tools, and connectivity.

[15] The New York Academy of Medicine: Project ECHO https://nyhealthfoundation.org/wp-content/uploads/2017/12/project-echo-evaluation-guide.pdf

v) Points 3a-u relate to palliative, health and social care access and delivery, but Marie Curie urges the Committee to consider wider public health aspects in the context of the remote and rural workforce strategy, including housing.

w) There is a lack of available accommodation for workforces in rural and remote areas, particularly island communities. This significantly impacts workforces' ability to deliver palliative care, as well as recruitment and retention, forcing many areas to rely on bank staff which is costly, and unsustainable long term.

x) There must be proactive engagement and contribution from Scottish Government's Housing directorate to the remote and rural workforce strategy, to ensure appropriate placement of new build housing in the long-term, which should be prioritised in particularly remote areas. Short and medium term solutions must also be explored.

4. What specific workforce related issues should the strategy look to resolve?

a) Workforce recruitment and retention continues to be the most significant issue which impacts end of life experience in rural, remote and island communities, and the strategy must seek to resolve this as a matter of urgency.

b) Issues with workforce recruitment and retention are particularly acute for specialist palliative care teams, as well as generalist teams, and the social care workforce. This places increased physical, emotional and financial burdens on carers of terminally ill people, who experience challenges with access to respite, self-care, emotional burdens, management of medications, isolation and loneliness, and grief.

c) Workforces are also ageing, and this challenge is felt acutely in rural, remote and island communities, and compounded by domestic migration of the working age population away from rural areas, particularly young people, to replenish such workforce[16].

d) Workforces also often have long travel distances either to patients, or other palliative care providers. In the context of terminal illness, this can be the difference between someone getting the support they at end of life, or not.

e) Workforces which do serve rural, remote and island communities are also more likely to care for someone they know because of smaller population sizes. The impact this has on patients as well as social care staff has not been widely captured, but must be considered.

[16] Jamieson, L & Groves, L 2008, Drivers of Youth Out-Migration from Rural Scotland: Key Issues and Annotated Bibliography. Scottish Government.

f) As well as workforce challenges in the delivery of community palliative care, acute settings such as rural hospitals often don't have access to the same specialisms as urban hospitals, including space, some equipment and digital connectivity. There often leads to an increased reliance on generalist care teams, including care homes, who are less likely to have formal palliative care training.

g) This lack of availability of resources in rural, remote and island areas makes accommodating end of life choices very difficult, and in many cases impossible altogether which puts increasing pressure on workforces.

5. Are there any workforce related issues which the creation of Remote and Rural Workforce Strategy alone will not address. If so, what are these issues and what additional action may be required to address them?

a) Urban centric palliative care commissioning models are traditionally used Scotland-wide, however, do not transfer appropriately to rural, remote and island communities because of unique challenges highlighted throughout this response.

b) Commissioning and health and social care models must also shift away from single disease models, as Marie Curie research has found that multi-morbidities are becoming the norm in Scotland, and rising steeply with age. People dying with multi-morbidities will also have increased by 80% by 2040.

c) Rural health and social care, and commissioning models must be culturally sensitive to support population health palliative care needs, in rural, remote and island communities, which will require participation from terminally ill people, carers, families, communities and health and social care professionals to better understand these issues and solutions.

d) A model for sustainable palliative care funding must also be considered and developed simultaneously to the Remote and Rural Workforce strategy to meet current and future palliative care demand in rural, remote and island settings.

e) The model must be agile to respond to varying palliative support needs in rural, remote and island communities which currently causes difficulty in sustaining workforce contracted locally.

f) Therefore, any sustainable funding model must consider dedicated rural, remote and island community commissioning across Integration Authorities which serve these populations to reflect local palliative support needs. In addition, a national commissioning funding model should also be explored, for example, for the proposed peripatetic model of multidisciplinary care delivery specific to local areas, which works in partnership with local teams and communities, enabling terminally ill people in island, rural and remote areas to die at home.

g) Marie Curie research has shown that two thirds of people in Scotland will be dying in community settings by 2040, including in people's own homes, care homes and hospices. We also know that the greatest increase in palliative care demand will be in over 85s in the coming years, which means rural, remote and island communities will require significantly increased palliative support as a result of having higher numbers of elderly populations.

h) It is vital that a sustainable palliative care funding model is developed as a matter of urgency, which reflects the unique needs of terminally ill people, their families and carers in rural, remote and island communities.

i) Without it, terminally ill people in rural, remote and island communities will be at risk of dying without some or all of the support they need.

About Marie Curie Scotland

Marie Curie is the largest third sector provider of palliative and end of life care services in Scotland for adults. In 2022-23, Marie Curie supported over 8,100 people in Scotland.

Marie Curie have two Hospices in Scotland, one Glasgow and one in Edinburgh. As well our inpatient services, the hospices offer outpatient services for terminally ill people and in some cases their bereaved loved ones delivered by clinical staff, allied health professionals and counsellors. Clinicians from both hospices also offer expert palliative support to generalist and community health and social care staff.

Marie Curie's Hospice Care at Home service is active in 31 of Scotland's 32 local authority areas. The exact Hospice Care at Home service Marie Curie provides differs by area but the key services we provide are:

- A "Managed Care" service where a clinical coordinator manages all aspects of a patients care to make sure they are fully supported at the end of life.
- A "Urgent Hospice Care at Home" service where a nurse or a social care assistant will respond to urgent calls for assistance.
- A "Sitting Service" where a nurse or a social care assistant will go to a terminally ill persons home and spend a block of time with them (often through the night) to provide care and provide respite for carers.
- A "Fasttrack" service where Marie Curie will provide comprehensive health and social care support to allow a terminally ill person to leave hospital without a care package from their local authority in place.

The Marie Curie **Information and Support** line can be called from anywhere in Scotland for practical or clinical information, and emotional support for someone living with a terminal illness, their carer or someone who has experienced a bereavement. Marie Curie's Helper and companion volunteer service supports tackling the social isolation many terminally ill people feel after a diagnosis.

Marie Curie is also the biggest charitable funder of palliative care research across the UK.

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