Pre-budget scrutiny 2026-27, with a focus on mental health spending

Response 899745212

Organisation details

Back to Response listing

Include unanswered questions

1. Name of organisation

(Required)

Mental Health and Wellbeing in Advanced Illness Network (MAIN)

2. Information about your organisation

MAIN, established in January 2024, is a research and knowledge exchange forum aiming to raise awareness of the importance of mental health and wellbeing in all aspects of advanced life-limiting illness, and inform the development of evidence-based approaches to improve access to mental health support people impacted by advanced illness. Through knowledge exchange and collaboration, MAIN engages a wide range of stakeholders in research, including academics, educators, health and social care professionals, psychologists, policy-makers, and people impacted by an advanced progressive illness. By connecting people from diverse settings with different areas of expertise we can share evidence, information and resources, which will help improve practice and influence policy and service innovation in this field. The network values innovation, inclusivity and purposeful action towards the goal of improving mental health and wellbeing support for people and their families in advanced progressive illness or end of life.

Current mental health spending

1. Is the level of spending on mental health services appropriate?

Please use this textbox to provide your answer

While the overall amount of mental health spending is encouraging, we believe that current spending does not consider the needs of people with advanced illness, long-term conditions, and those requiring

palliative care. These groups remain largely invisible in funding decisions, despite well-documented evidence of significant mental health needs. Meta-analytical and longitudinal research suggests that 25-30% of people in palliative or oncological settings meet clinical criteria for mood disorders (Mitchell et al., 2011), and 80% exhibit clinically meaningful symptoms of anxiety or depression at one or more time points (Sewtz et al., 2021). Mental health support is also crucial for those close to them, particularly family members and close friends, who may experience considerable emotional distress as they provide care and cope with anticipatory grief (Liu et al., 2019; Moghaddam et al., 2023).

The current focus of funding priorities is heavily skewed towards early-life interventions, particularly children and young people, without a true life-course approach. This leaves a “missing middle” of working-age adults and older adults whose mental health needs often emerge or intensify due to illness, disability, bereavement, and social isolation. The Life Stage Model outlined in the Mental Health and Wellbeing Strategy (2023) makes no reference to the last phase of life, specifically the period following diagnosis of an advanced progressive illness (e.g., advanced cancer, dementia, heart failure), despite this being a phase of life that often heightens mental health problems such as anxiety, distress, depression and adjustment difficulties, both for the terminally ill person and those close to them.

We urge policymakers to ensure explicit allocations for people impacted by advanced illness in future budgets, either through adding a dedicated priority or recognising their needs within all existing priorities.

Liu et al. (2019): https://doi.org/10.1371/journal.pone.0214838

Mitchell et al. (2011): https://doi.org/10.1016/S1470-2045(11)70002-X

Moghaddam et al. (2023): https://doi.org/10.3389/fpsyg.2023.1059605

Sewtz et al., (2021): http://doi.org/10.21037/apm-20-1346

2. What information can help support assessment and evaluation of the allocation of the mental health budget?

Please use this textbox to provide your answer

Reporting on the mental health budget tends to focus on inputs (e.g., the number of mental health nurses employed) rather than on impacts relating to access, outcomes, and quality of care. There is no systematic intersectional analysis showing how deprivation, ethnicity, co-morbidities, and rurality intersect to affect need and access. Crucially, this gap includes palliative and end-of-life care, where the absence of routine data obscures the extent of need, and the effectiveness of support provided. We recommend that disaggregated data by life stage, condition (including advanced and terminal illness), and care setting be routinely collected and published, alongside impact measures that capture outcomes across the life course. This would allow the public and policymakers to see not just where money is spent, but what it achieves for groups whose needs are currently less visible.

Preventative spend on mental health

3. Do you consider there to be evidence of preventative spending activities in relation to mental health (and if so, can you provide examples)?

Please use this textbox to provide your answer

In Scotland, there is an almost complete absence of sustained preventative spending on psychological support for people affected by an advanced progressive illness and those who benefit from palliative care. Currently, there is less than the equivalent of one full-time specialist psychological

post dedicated to palliative care nationwide. Where these services do exist, they are typically locally driven, often reliant on an “interested individual,” short-term in nature, and lack dedicated funding.

Yet, there is strong evidence that brief psychological support interventions can enhance wellbeing for people with advanced illness and for those close to them. International examples include CALM (Managing Cancer and Living Meaningfully (Kool et al., 2023; Loughan et al., 2022; Rodin et al., 2018), Acceptance and Commitment Therapy (Watt et al., 2023), Dignity therapy (Martínez et al., 2016) as well as mindfulness interventions (Tan et al., 2023). Digital mental health interventions can also play a role in supporting wellbeing towards end of life, or for people who have been bereaved (Finucane et al., 2021; Finucane et al., 2024). For example, My Grief My Way (https://mygriefmyway.co.uk) is an online bereavement support intervention based on Acceptance and Commitment Therapy that is freely available to support coping and mental wellbeing amongst people who have been bereaved.

We believe that investment in preventative, evidence-based interventions for people impacted by an advanced progressive illness or bereavement could:

- Reduce downstream service use by carers and bereaved families.
- Mitigate the long-term mental health impacts on friends, unpaid carers, and staff.
- Provide cost-effective support through stepped-care models, training generalist staff to deliver basic psychological interventions, and using digital platforms to extend reach.

Dona et al. (2024): https://doi.org/10.1186/s12913-021-07212-7

Finucane et al. (2021):

https://doi.org/10.1038/s41746-021-00430-7
Finucane et al. (2024): https://doi.org/10.1177/0269216241285101
Kool et al. (2023): https://doi.org/10.1002/pon.6281
Loughan et al. (2022): https://doi.org/10.1007/s11060-022-03988-8
Luta et al. (2021): https://doi.org/10.1186/s12904-021-00782-7
Martínez et al. (2016): https://doi.org/10.1177/0269216316665562
Rodin et al. (2018): HTTPS://DOI.ORG/10.1200/JCO.2017.77.1097
Tan et al. (2023): https://doi.org/10.1136/bmjspcare-2021-003349
Watt et al., 2023: https://doi.org/10.1177/0269216323118310

Priorities for mental health spending

4. Do you consider these to be the right priorities for mental health investment?

Please use this textbox to provide your answer

While we recognise the validity of these priorities in principle, they appear disproportionately child- and youth-focused, with little explicit recognition of adults or older adults with advanced illness or long-term conditions.
This absence reflects a policy narrative that assumes early-life interventions alone will prevent later-life mental health needs, overlooking the fact that a great deal happens in middle and later life that can significantly challenge mental wellbeing.
We therefore call for either an explicit additional priority for adults with advanced progressive illness, long-term conditions, and palliative care needs, or for these groups to be named in each existing priority so their inclusion is clear.

5. To what extent are these priorities reflected in mental health service delivery?

Please use this textbox to provide your answer

Service delivery is inconsistent and often absent for people living with advanced illnesses. For example, Distress Brief Interventions, one of the Government's flagship measures, rarely reach people in palliative care or those living with long-term conditions. Where they do exist, they are typically targeted at acute episodes of mental distress unrelated to physical illness, rather than integrated into holistic care for those with complex health needs.
In addition, access to specialist mental health support varies widely by region, creating a postcode lottery. Many primary care teams and community mental health teams are overstretched, resulting in long waits and limited capacity for proactive, preventative work. Even when skilled staff are present, systemic bottlenecks (e.g., lack of social care or housing) prevent people from being discharged or living well at home, undermining the effectiveness of mental health services.

Decisions on mental health spending

6. How could transparency in relation to decisions around mental health spending in Scotland be improved?

Please use this textbox to provide your answer

We believe transparency must go beyond simply publishing budget lines. It should show how money is actually deployed, commissioned, and what tangible outcomes it achieves. This could include:
1. Clear, public-friendly explanations of the funding flow (Scottish Government → health boards → Health and Social Care Partnerships → service providers).
2. Outcome-based reporting with meaningful measures, such as GP referral success rates, patient access times, and reduced delayed discharges. For people with an advanced progressive illness, this would include the proportion with a Key Information Summary, and within this, evidence of an advance care plan.
3. Capturing wider system impacts. For example, how mental health investment interacts with social care, housing, and community services.
4. Greater clarity on commissioning cycles and decision-making processes, so that stakeholders can engage at the right time.
We also recommend the introduction of minimum service standards for mental health provision across all life stages and care settings, including palliative and end of life care and for those accessing hospice care, ensuring a baseline level of psychological support for those with advanced illness and palliative care needs.