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Open call for evidence

Informing the mental health strategy for England

Responses submitted on behalf of the Mental health and wellbeing in Advanced Illness Network (MAIN)

[26th June, 2026]

About MAIN:

The Mental health and wellbeing in Advanced Illness Network (MAIN) is a research and knowledge exchange forum that aims to share research evidence and good practice to improve the mental health and wellbeing of people impacted by advanced progressive illness across the United Kingdom. See: https://www.mainexchange.org.uk/

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1. Hospital to community

1.1 How can mental health services work more effectively across these areas?

1. Recognition of the mental health and wellbeing needs of people with advanced progressive illness: Psychological distress is common among people with advanced progressive illness, including advanced cancer (Hart et al., 2022; Mitchell et al., 2011) , organ failure (Rashid et al., 2023; Shea et al., 2024), dementia (Leung et al., 2021), and multimorbidity (Farooq et al., 2019; Read et al., 2017). Approximately 29% of people with advanced cancer experience clinically significant anxiety, depression or adjustment disorder (Mitchell et al., 2011), with some studies reporting rates as high as 80%, depending on disease stage and time since diagnosis (Sewtz et al., 2021). Nearly 60% of people referred for hospice care have psychological support needs (Finucane et al., 2021), and nearly half receiving hospice-at-home services experience moderate-to-severe anxiety or depression in the last week of life (Kozlov et al., 2019). Carers are also affected, with a pooled prevalence of 31% for high existential distress (Walbaum et al., 2024). Despite this, mental health needs of people with advanced progressive illness and their carers remain under-recognised, limiting access to appropriate support. The new mental health strategy must explicitly recognise these needs to ensure timely access to appropriate mental health and wellbeing support.

2. Stepped care models of support for people with advanced illness: Effective and cost-effective mental health support for people with advanced illness should follow a stepped-care approach, ranging from low-intensity to specialist care for complex needs. Our network (MAIN) proposes a 5-step model of support comprising (see: https://www.mainexchange.org.uk/about/position-statement/): Level 1, online self-directed support; Levels 2-3, psychological support for those struggling to adjust to advanced illness, delivered by healthcare professionals trained in mental wellbeing support; and Levels 4-5, specialist mental health care for people with advanced illness and pre-existing mental health problems or severe mental illness (SMI).

1.2 What further support should be provided for people with severe and enduring mental illness?

1. Outreach palliative care for highly marginalised groups: Initiatives such as the Palliative Education and Care for the Homeless (PEACH), a community-based palliative care program for people experiencing homelessness in Toronto, Canada, can improve mental wellbeing for those typically underservice by healthcare services (Levesque et al., 2026; Nicole Buchanan & Trevor, 2023; Robinson et al., 2023). Such models highlight the value of formal, integrated partnerships across medical, psychosocial, homecare, housing services to improve outcomes for homeless people with advanced illness. PEACH helps eliminate systemic barriers, improves physical and mental well-being, and addresses social determinants of health through a compassionate, person-centred approach (Levesque et al., 2026). Some individuals accessing PEACH emphasized the importance of embedded mental health care that also help overcome longstanding barriers to psychiatric support.

2. Named care navigators spanning hospital and community care: Care navigators can provide assistance to patients and carers in navigating complex health and social care systems to overcome barriers in accessing quality care and treatment. In Western Australia, the Compassionate Communities Connectors involves enlisting community volunteers to enhance supportive networks that can provide practical and social support to people with advanced illness, optimising palliative care service utilisation, improving patient outcomes and reducing healthcare costs (Aoun et al., 2023).

3. Housing support: People with SMI and an advanced progressive illness often experience multiple disadvantages extending beyond healthcare. Support could be improved by (i) implementing targeted measures to remove barriers to accessing housing following diagnosis of an advanced illness and (ii) providing trauma-informed psychosocial and spiritual support that addresses intersecting needs of people experiencing both homelessness and serious illness (Johnson et al., 2024). See also https://www.mariecurie.org.uk/document/dying-in-the-margins-2023 for further recommendations on supporting terminally ill people experiencing multiple social disadvantages.

1.3 What are the main barriers to continuity of care across transitions between hospital and community services, and between different levels of care, including child to adult services?

1. Fragmentation between services and unclear ownership: A major barrier is the lack of integration between mental health, physical healthcare, and palliative care, leading to unclear responsibility for meeting mental health needs in advanced illness. Palliative care professionals often lack time, training or systematic support to provide adequate psychological care (O'Malley et al., 2021; Paley et al., 2024; Zavery et al., 2025), and most teams lack dedicated access to mental health specialists (McInnerney et al., 2021). This limits staff training and supervision in psychological support care provision, and contributes to suboptimal screening and treatment of mental health conditions among those with advanced illness. Similarly, mental health practitioners may lack confidence in incorporating physical deterioration, prognosis, treatment burden, existential distress, total pain, family systems and end of life decision-making into assessment and formulation.

2. Delayed access and inappropriate care for people with SMI: People with SMI may experience delayed access to palliative because of late presentation of illness and poor communication between psychiatric and palliative or primary care providers. Similarly, palliative care staff often encounter barriers to accessing timely psychiatric/psychologist input for patients with SMI, resulting in worsening psychiatric symptoms as health deteriorates. In a survey completed by 151 hospice staff, 54% reported unclear referral guidelines; and 36% felt unable to arrange psychological support when needed (Zavery et al., 2025). Some palliative care settings may be ill-equipped to support people with SMI, increasing the risk of discharge to inappropriate settings(Donald & Stajduhar, 2019). Integrated pathways, such as that proposed by the collaborative care model centres around a multidisciplinary care team, such as primary care physicians, consulting mental health clinicians, and case managers who facilitate coordination of care, and is now proposed as a useful model for the integration of palliative care and mental health service delivery (Wozniak et al., 2021)

2. Analogue to digital

2.1 What evidence and innovative examples are there of digital and AI tools being used to achieve these outcomes?

1. Online mental wellbeing support provides timely access to low-intensity support mental wellbeing support for people impacted by advanced illness. Resources such as MyGrief MyWay (https://mygriefmyway.co.uk/) provide timely bereavement support regardless of location (Canny et al., 2025; Finucane, Canny, Harrop, et al., 2025; Gillanders et al., 2025).

2. AI-assisted tools are already showing promise in mental health and palliative care for routing screening for mental health and palliative care needs, including symptom tracking and self-management, with emerging evidence that these technologies reduce delays in care (Ni & Jia, 2025; Xu et al., 2026). Conversational artificial intelligence including therapeutic agents and chatbots, may reducing symptoms of depression and distress (Li et al., 2023) and could be developed to provide tailored support to people with mental health support needs alongside advanced illness.

3. Virtual consultations: Many patients with an advanced progressive illness may not feel well enough to travel to appointments, or to travel alone. While in-person meetings may be needed to assess physical symptoms, online or virtual consultations are increasingly accepted by patients and families, and can be a more efficient way of providing mental wellbeing support to people with an advanced progressive illness (Morris et al., 2024).

4. Reducing social isolation: Virtual peer support groups and online communities can be particularly helpful where a person feel stigma or finds it hard to talk about their experiences, for example, following bereavement as a result of suicide (Finucane, Canny, Mair, et al., 2025).

5. Virtual reality: Personalised virtual reality therapies can be an effective approach to relieving physical and psychological pain and support self-awareness (Huang et al., 2024). One-off virtual reality sessions with patients at St Columba's hospice in Edinburgh were acceptable and enjoyed by patients, offering patients the capacity to reconnect with a previous sense of self (Lloyd & Haraldsdottir, 2021).

2.2 How can data be used more innovatively to improve mental health and wider societal outcomes?

1. Better integration of data across NHS, social care, housing, and community services could enable earlier identification of unmet mental health, social care, and palliative care needs, for people who are at risk of falling between services. Currently, information is often held in separate systems, limiting proactive identification of mental health deterioration, repeated hospital admissions, housing instability, and delays in care. Integrated datasets could support earlier intervention and discharge planning. For example, in neurorehabilitation, people with SMI and life-limiting neurological conditions often experience prolonged hospital stays due to delays in housing, care packages, or community support (Gosling & Mishra, 2023). Better use of integrated data could identify these barriers earlier, allowing discharge planning to begin sooner and reducing unnecessary time spent in hospital.

2. Monitor outcomes important to the person: Data should be used to monitor outcomes that matter most to patients, including psychological distress, social connectedness, psychological wellbeing, and quality of life, alongside physical wellbeing and service metrics.

3. Predictive analytics: Predictive analytics may also help identify people with advanced progressive illness at increased risk of psychological distress, social isolation, repeated crisis presentations, or carer breakdown, enabling earlier referral to mental health, social care, or VCSE support. For example, repeated admissions, missed appointments, escalating support needs, or delayed discharges could trigger proactive multidisciplinary review.

4. Identification of inequalities in access to services: People with severe and enduring mental illness often experience poorer access to palliative care, psychological therapies and community services (Donald & Stajduhar, 2019; Hannigan et al., 2022; O'Connor et al., 2026). Routine collection and analysis of data on access, waiting times, outcomes, and discharge destinations could help commissioners and providers identify gaps in provision and target resources more effectively.

3. Sickness to prevention

3.1 Which preventative approaches have the strongest evidence for reducing incidence or severity of mental health problems and promoting good mental health?

1. Early routine mental health and wellbeing assessment: Distress screening tools, e.g., the Distress Thermometer, are widely used across healthcare settings to identify concerns early and have been validated for use in palliative care (Graham-Wisener et al., 2021; Ownby, 2019; Tuinman et al., 2008). The Distress Thermometer can be used by healthcare staff without specialist mental health training. Screening for distress in advanced illness is essential to identify problems early on, and should routinely be undertaken by healthcare professionals.

2. Interventions that strengthen coping and resilience: Psychological interventions such as Acceptance and Commitment Therapy (ACT) (Gibson Watt et al., 2023), mindfulness (Howarth et al., 2019), dignity therapy (Yanez et al., 2025) and meaning-centred therapies (Shen et al., 2025; Zhang et al., 2025) can reduce distress by promoting adaptive coping, increasing psychological flexibility and meaning-making. Such interventions, especially when brief and flexibly delivered, are particularly valuable when offered as part of a stepped-care model of mental wellbeing support for people with advanced illness (Levels 3 and 4). For example, an ACT plus usual care intervention was cost-effective and maintained or improved quality-of-life in people with Motor Neuron Disease (Gould et al., 2024; Keetharuth et al., 2024), while four-session Managing Cancer and Living Meaningfully interventions mitigated distress (Zhang et al., 2025).

3. Strengthening social support: Social isolation is a major risk factor for poor mental health in advanced illness. Peer support, community-based initiatives, and support for carers can enhance social connectedness and wellbeing (Maun et al., 2026; Theißen et al., 2024).

4. Strengthening workforce capability: Training the wider health and social care workforce to recognise emotional distress, communicate compassionately, and provide low-level psychosocial support (Levels 2 and 3) is feasible and can strengthen prevention of severe mental health difficulties (Kool et al., 2024; Mannix et al., 2006; Zavery et al., 2025).

3.2 Which preventative approaches have the strongest evidence for reducing the number of lives lost to suicide?

1. Strengthening integration between mental health and palliative care services: For people with an advanced progressive illness, suicidal ideation or "desire for hastened death" may reflect modifiable sources of distress rather than a fixed wish to die. Preventative approaches include (i) Prioritised/rapid access to psychological and/or psychiatric support and specialist palliative care services; (ii) Continuity of care, for example by ensuring a community mental health nurse maintains contact with the person after referral for palliative care, offering advice to the palliative care team and advocating on behalf of the person; and (iii) Availability of a consultant psychiatrist to input to palliative care multidisciplinary teams.

2. Prevention: For people with SMI, prevention requires the development of a robust, shared psychological formulation and safety plan. A clear formulation that identifies what specifically drives distress and escalates risk for that individual can be highly stabilising. When translated into a practical safety plan, this can support earlier recognition of deterioration and more coordinated responses, rather than crisis-driven escalation. Clinical psychologists embedded in palliative care multi-disciplinary teams can provide formulation, supervision, training and specialist intervention for high psychological complexity. Where there is severe mental illness or significant self-harm/suicide risk there needs to be integrated care planning with specialist psychiatric input.

3. Early identification and active treatment of depression, anxiety, and demoralisation for people with an SMI and advanced illness with Level 4 support, i.e. regular one-to-one support provided to the individual by a clinical psychologist and/or psychiatrist.

4. Proactive enquiry about suicidal ideation: Routine, repeated enquiry about suicidal ideation and desire for hastened death, particularly at points of deterioration, transition, or loss of independence, rather than relying on passive disclosure. To support this, there is a need for healthcare professional training in how to ask about death wishes, suicidality and fear without panic or avoidance.

3.3 How can services better support the 'missing middle' - those with sustained needs (that affect their participation in community life, for example, in education or work) who may not meet the criteria for NHS mental health services? Please provide examples.

1. Training: All health care professionals supporting people with advanced progressive illness would benefit from brief, focused psychological skills training to support patients and carers during routine consultations. Furthermore, all professionals working with people affected by advanced progressive illness should be equipped to recognise and respond to psychological distress as part of routine care. At the same time, mental health specialists need training in providing mental health support for people with an advanced progressive illness, as well and those caring for them.

2. Integrating psychology within services supporting people with advanced progressive illness: In specific areas, such a neurology, embedding psychology (including neuropsychology and health psychology) directly into neurology clinics and specialist rehabilitation services would allow earlier intervention for adjustment difficulties, emotional distress, and participation restrictions (Trapp et al., 2022). For example, a person with a progressive neurological condition who has stopped working due to fatigue and cognitive changes could be offered brief psychological formulation and ACT-based intervention within neurology follow-up, rather than being told they do not meet Community Mental Health team criteria. This could prevent escalation into severe depression and social withdrawal. Low-intensity psychological interventions (e.g., guided self-help, group-based ACT, psychoeducation, peer support) show promise, while referring to mental health specialist services for higher-intensity input as needed. For example, an ACT programme delivered through a neurorehabilitation community team for people with progressive neurological conditions such as Huntington's, struggling with loss of role and identity, could support values-based adaptation and community re-engagement (Buswell et al., 2024).

4. Factors enabling good practice

What commissioning, funding and oversight or accountability arrangements (nationally and locally) best support safe and integrated mental health services that improve outcomes across mental health, participation in work, education and community life, and social functioning? Please provide examples.

1. Commission condition-based or pathway-based models for advanced progressive illness (e.g. oncology, dementia, neurological conditions, acquired brain injury, spinal cord injury pathways), with embedded psychological provision across the entire trajectory. Access to psychological input aligned with need should be available from diagnosis of an advanced progressive illness. This would also support continuity across oncology/neurology/dementia, rehabilitation, and palliative care.

2. Increasing access to mental health specialists This would mean embedding psychologists within oncology/neurology and dementia teams. Mental health specialists would provide psychological support to those most in need, while supervising healthcare professionals to deliver good basic evidence based psychological support. Embedding psychological support within care pathways prevents psychology becoming an optional add-on; and ensures prevention and early intervention as opposed to crisis-driven input. This may in turn reduce downstream demand on Community Mental Health teams and crisis services.

3. Integrated Care Systems (ICS) accountability for mental health outcomes in long-term conditions: Currently ICS accountability for mental health outcomes in physical health pathways is limited and diffuse. ICSs might explore reporting on psychological wellbeing outcomes in long-term neurological and advanced progressive conditions, not just acute mental health indicators. This could include distress levels in palliative cohorts, crisis presentations post-discharge, access to psychological input across advanced progressive illness pathways, and carer burden indicators. This would make psychological care a system performance issue, not an optional enhancement and would drive investment into prevention rather than crisis response.

5. Your local mental health strategy or delivery plan

If you're answering on behalf of a mental health trust, integrated care board or local authority, please provide your local mental health strategy and/or delivery plan so we can learn from your work.

You can upload your strategy or plan as a file. If it's available online, you can provide a link to it instead.

https://www.mainexchange.org.uk/about/position-statement/

Are there any examples of particularly effective services, programmes, or policies in palliative care in your local region that the England Government should learn from?

If you could recommend one or two priority actions for the new Mental Health Strategy in England to support people affected with advanced illness, what would they be, and why?

1. Mandate integrated, embedded psychological care within physical health pathways associated with advanced progressive illness (especially neurology and rehabilitation). Psychological support needs to be part of the core medical pathway, not something accessed only via long waiting lists, or community mental health thresholds or crisis referral.

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