Mental Health and Wellbeing in Advanced Illness Network (MAIN)

Position statement

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Foreword

Everyone affected by a life-limiting illness, dying, death and bereavement should have access to effective mental health and wellbeing support. I am delighted to support the launch of the Mental Health and Wellbeing in Advanced Illness Network (MAIN). By fostering research collaboration and knowledge exchange, MAIN will accelerate progress towards this vision.

In the UK, each year over 600,000 people die because of a life-limiting illness, and many more are bereaved. A life-limiting illness brings with it significant challenges for mental health and wellbeing, made worse by unfavourable personal, social, economic, and environmental circumstances

While some people cope well and adapt to their circumstances, a significant proportion of people are overwhelmed by anxiety, distress, sadness, hopelessness, and low mood in the face of uncertainty and loss. This results in poor quality of life, barriers to communication, and for some a desire for a hastened death.

There is a need to bring together, share and grow the evidence base on people's mental wellbeing experiences in the last stage of life – both in relation to coping well and not so well. There is much to do in the space, so the work of MAIN is very welcome.

I wish the network every success.

Dr Sam Royston
Director of Policy and Research, Marie Curie

Introduction

The Mental Health and Wellbeing in Advanced Illness Network (MAIN), 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. It is for researchers, health and social care professionals, policymakers, educators, and the public. The network will provide opportunities for sharing research evidence on mental health and wellbeing towards end of life, prioritise research questions and encourage collaborations to address research gaps. Our vision is that everyone impacted by an advanced life-limiting illness has improved access to mental wellbeing support and that scientific research in this area progresses.

Our guiding principle:

Mental health and wellbeing have equal value to physical health and wellbeing.

Mental health and wellbeing across the UK: A policy perspective

England

In England, the commitment to achieving genuine parity of esteem between physical and mental health, i.e. valuing both equally, is embodied in the *NHS Five Year Forward View* (2014) with further commitments towards improving mental health in the *Five Year Forward View for Mental Health* (2016) and the *NHS Long-Term Plan* (2019).[1-3] In particular, there is a pledge to deliver more integrated care, which responds to the person as a whole rather than dealing with physical and mental health conditions separately and a commitment to tackle health inequalities. Despite efforts to significantly increase access to and provision of services such as talking therapies, social prescribing and mental health support within primary care networks, full parity of esteem is still some way off.
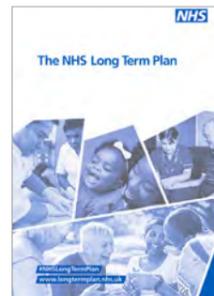
A statutory duty to commission palliative care services was established by the *Health and Care Act 2022*.[4, 5] This locates responsibility for commissioning palliative care with Integrated Care Boards. Mental health and wellbeing is also addressed in strategies such as the Major Conditions Strategy Strategic Framework and the *Suicide Prevention Strategy for England* (2023-2028).[6, 7] These set out a shift to integrated whole person care and create a context within which palliative care and bereavement support is more expressly integrated within services.

Scotland

Several policies in Scotland acknowledge both the importance of mental health and the role of palliative care in supporting
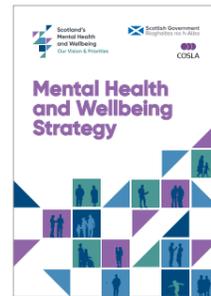
this. This includes the current mental health and wellbeing strategy delivery plan which highlights psychological interventions for people living with long term health conditions and the importance of early identification of poor mental health risks.[8]

Wales

In Wales there is palliative and end of life care quality statement and a bereavement framework.[9, 10]. The latter recognises that unresolved grief issues can lead to serious mental health difficulties. The Welsh Government has committed to consulting on a new mental health strategy this year, which will provide an opportunity to highlight the relationship between physical illness and mental ill health.

Northern Ireland

In Northern Ireland the *Mental Health Strategy* (2021-2031) seeks to ensure that those with a physical illness that causes mental ill health can receive the care and treatment they need.[11] *A Cancer Strategy for Northern Ireland* (2022-2032) also makes significant reference to bereavement support and palliative care.[12]
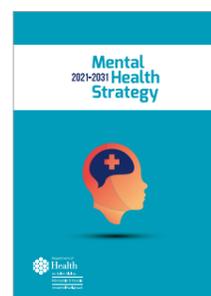
Mental health across the life course

Mental health is essential for general health and wellbeing throughout life.[13] It is about feeling good and being able to do the things that matter. This is important from birth right through to the very end of life. A person with good mental health can regulate their emotions and feelings, think clearly, and has positive relationships with the people around them. Good mental health enables people to cope with the stresses of life and to realise their abilities at school, work, or within their wider community.

Mental health is not a fixed state and varies over time. It is experienced differently from one person to the next. Individual, social, and cultural factors impact mental health and wellbeing. Poverty, violence and childhood adversity increase a person's risk of experiencing poor mental health. Protective factors such as positive relationships, good education, work opportunities, and safe environments serve to strengthen resilience and protect people against mental health problems.

The life-stage model is used to highlight certain stages in life which can significantly impact a person's mental health and wellbeing. Such stages include the period around childbirth, early years, childhood and adolescence, adulthood, and older adulthood. The Scottish Government use the life-stage model as a basis for the Scottish mental health and wellbeing strategy (Figure 1).[8] Each stage comes with different stressors and concerns, and problems at an earlier stage can increase the risk of problems later, so early intervention is key.

Figure 1: The Life Stage Model forms a basis for Scotland's mental health and wellbeing strategy[17] but does not explicitly acknowledge the palliative or end of life stage.

The Life Stage Model

- Preconception care
- Perinatal mental health care
- Parent-infant relationship mental health care
- Infant and early years mental health care
- Children, young people and family mental health care
- Adult and older adult mental health care
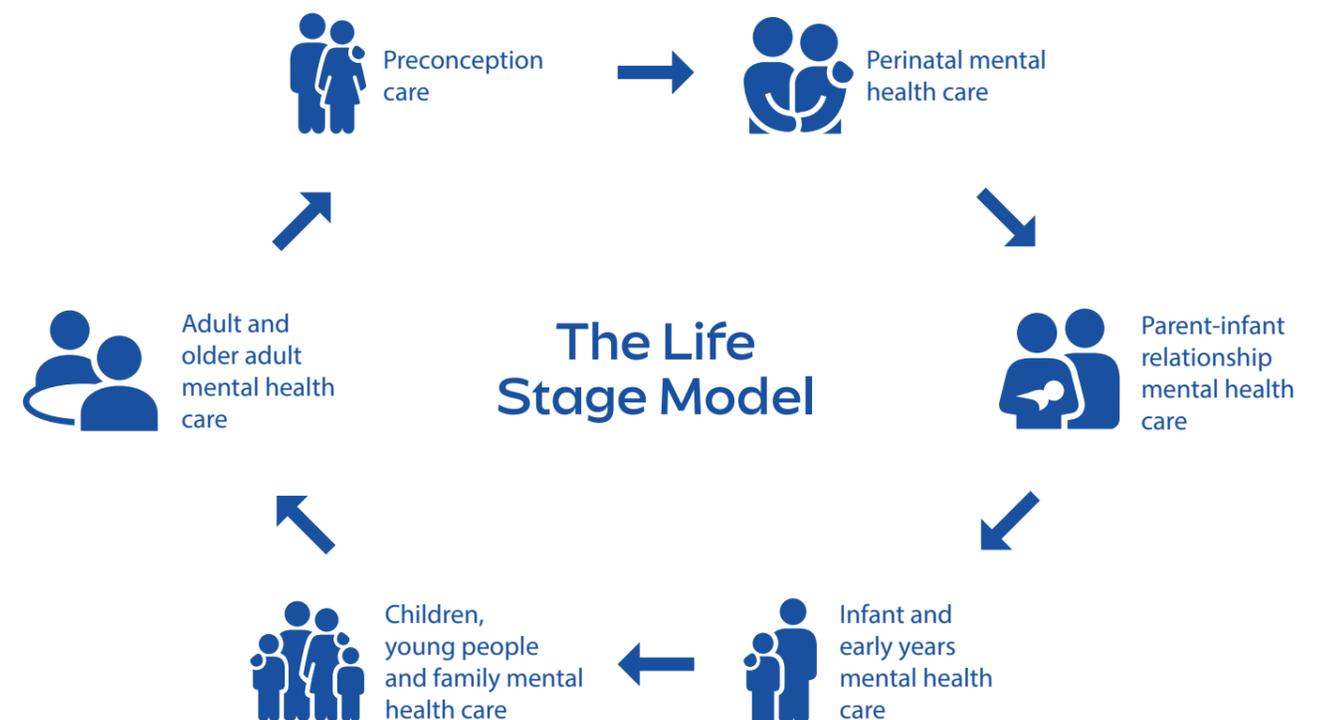
A key stage missed by the life-stage model is the period following diagnosis of an advanced life-limiting illness such as advanced cancer, heart disease, dementia, frailty, or a combination of illnesses. This typically occurs late in life, though can occur at any point, and represents a significant challenge to the mental health and wellbeing of the person with a life-limiting illness and those close to them.[14] For instance, some people need to balance serious life-limiting illness, or related caregiving duties, alongside their work or studies, resulting in significant stress, anxiety and sleep deprivation.

In the UK, at least 90% of people will die of an advanced progressive illness, which equates to over 600,000 people each year. [15] Many more people will be bereaved.

The UK is often ranked as one of best performing countries in terms of palliative care development.[16] Excellent palliative and end of life care necessitates that the mental health and wellbeing of people with a life-limiting illness is recognised, and appropriate information and support is widely available.

> **MAIN seeks to raise awareness of the importance of mental health and wellbeing following diagnosis of an advanced life-limiting illness, and following bereavement.**

Prevalence of mental health problems

Mental health problems are common in general, with one in four people experiencing a mental health problem each year, and **one in six experiencing a mental health problem in any given week.** [18, 19] A serious life-limiting illness brings with it significant additional physical, psychological, social, and spiritual concerns. The prevalence of any mood disorder towards the end of life is around 29%. One in every three or four people will experience depression, anxiety, adjustment disorder or low mood.[20] However, these rates refer to those formally assessed as having a mood disorder. Many more will experience anxiety, distress, worry and low mood as a natural response to a terminal diagnosis. Approximately six in ten people referred for hospice care in the UK have psychological support needs.[21]

> **MAIN provides a forum to share evidence on the prevalence of mental health and wellbeing problems and concerns for people with a serious life-limiting illness, and to explore the implications for policy, service development and clinical practice.**

Children and young people

In the UK, the number of children with life-limiting conditions has risen over the past two decades. For instance, in England, 86,625 children had a life-threatening condition in 2017/18, an increase from just under 33,000 in 2001/02. While the increase may be attributed to better record-keeping, it is also likely to be the result of better care early in life and technological advances.[22]

Children's palliative care differs from that of adults. Conditions are often rare and complex, genetic conditions may affect more than one child, and communication and understanding can be challenging given the child's age. Palliative care needs to be focused on the child and their family while opportunities for play and education need to be maintained.[23]

The National Institute for Health and Care Excellence (NICE) quality standards for end of life care of infants, children and young people recognise the importance of emotional and psychological support for children and their carers, alongside support for grief and loss.[24] Yet, while studies provide evidence of burden and distress amongst parent caregivers, this rarely translates into improvements in practice through the development of interventions.[25] Better recognition, assessment and support of the mental health needs of children impacted by life-limiting illness, as well as their parents, carers and siblings, is needed.

Parental illness can have a major impact on a child's emotional wellbeing, and their social and school behaviour, causing additional stress, worry and anxiety for their parents or carers. Appropriate support for the child or young person is essential, as is advice for parents working out how to support their family while navigating serious illness.

> **MAIN provides a forum for research collaboration and knowledge exchange activities focused on the mental health and wellbeing of children and young people with a life-limiting illness and their families.**

Inequalities in risk of mental health problems and access to support

Risk factors for many common mental disorders are strongly linked with social inequalities, whereby the greater the inequality the higher the risk.[13] Specific risks include poverty, deprivation, poor housing, unfavourable social, geopolitical and environmental circumstances.[26]

Ethnic minorities, those living in remote and rural settings, and people living in poverty are less likely to receive specialist palliative care.[27] LGBTQ+ individuals face a host of issues relating to a longstanding history of bias, discrimination and marginalisation, which can lead to avoidance of health encounters or non-disclosure of their relationships or gender identity[28] and services are often not designed to serve their needs.[29]

Social and family circumstances can reveal significant inequalities in access to support and resources. For instance, single parents have additional pressures and responsibilities in all life elements, including time and availability restrictions and financial burdens, especially where they don't have a personal support network. This can seriously impact a person's mental health.

People with severe persistent mental illness experience a greater burden of disease, and die at a younger age, yet they often receive care in inappropriate settings with limited palliative care input.[30] Research is needed to address inequities in access to mental health and wellbeing support for people who are typically underserved.

> MAIN recognises inequalities in access to mental health and wellbeing support for people with a life-limiting illness and promotes research that progresses thinking on how mental health and wellbeing services can be designed to meet the needs of underserved populations.

University of Glasgow

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DYING IN THE MARGINS
The Cost of Dying Exhibition

The first research study in the UK to use visual methods to evidence circumstances of dying at home in financial hardship

UKRI Economic and Social Research Council

Measuring outcomes relating to mental health and wellbeing

An advanced life-limiting illness can cause considerable psychological distress including anxiety, depression, discouragement, and hopelessness. This can lead to suffering, poor quality of life, vulnerability, communication problems and in some cases an acute admission or desire for a hastened death.[31] Coping problems, caregiver burden and increased need for community healthcare services can also occur. For some people, there is a stigma attached to mental health, making it harder for people to take about personal mental health issues.

More research is needed to develop and test outcome measures that can be used to examine the effectiveness of interventions seeking to improve mental wellbeing. Research on approaches and outcomes linked with promoting greater openness to discussing mental health and wellbeing early on in a person's illness journey is also warranted.

Tools such as the Distress Thermometer have much potential,[32] but clinicians and service managers need more information on their use. Guidance is also needed on which wellbeing measures are best to use routinely in clinical practice, and when to choose a generic measure such as the iPOS (https://pos-pal.org/) over a more specific one such as the distress thermometer. People with a life-limiting illness must play a central role in the development or evaluation of any tools or measures to assess their wellbeing.

> MAIN will promote and share high-quality research that seeks to develop outcome measures that quantify the effectiveness of interventions to improve mental wellbeing in people with a life-limiting illness, their families, caregivers and close persons.
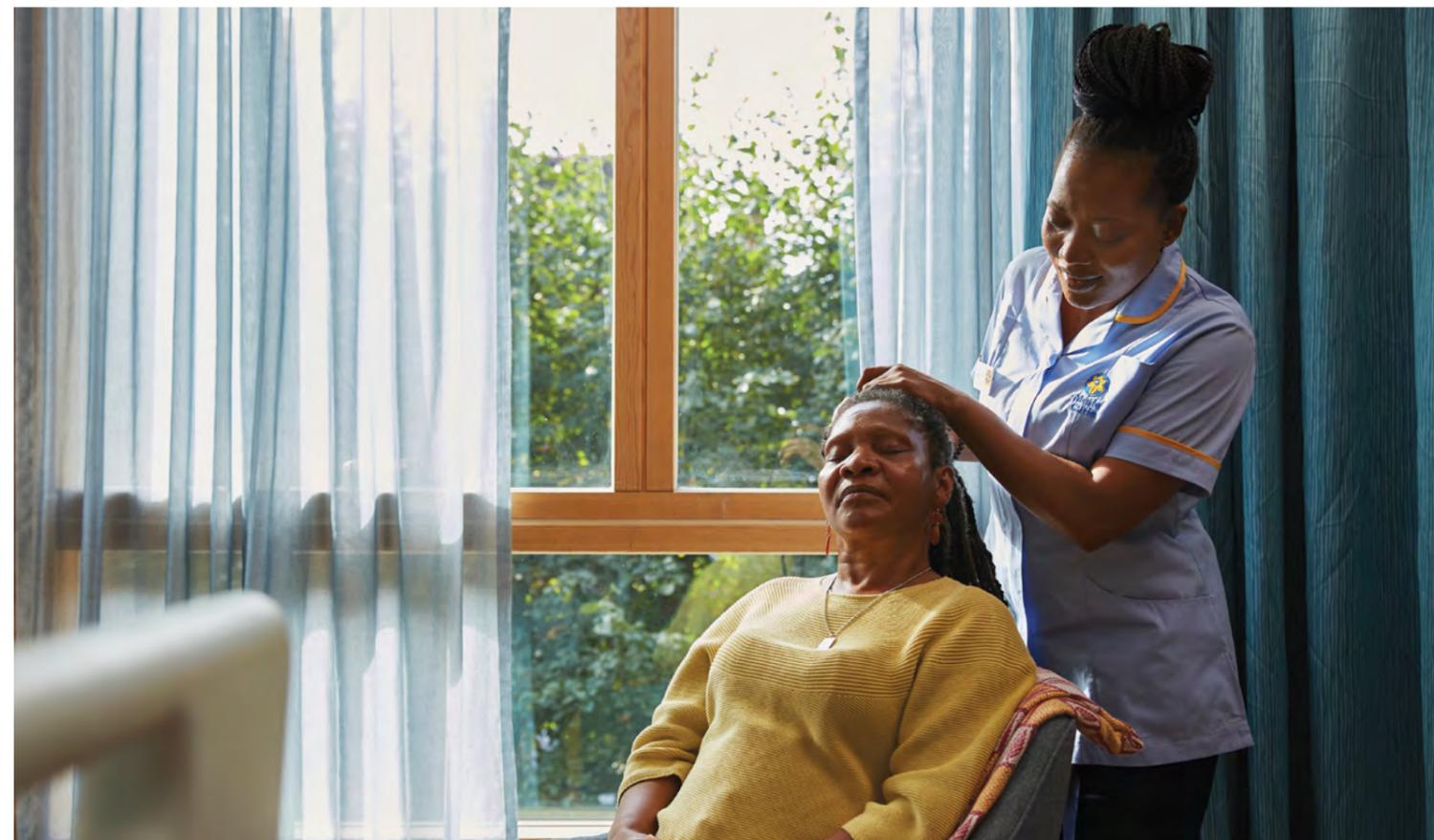
Mental health and wellbeing needs assessment

There is a wide variation in how people respond to an advanced life-limiting illness. This can be influenced by their social networks, life-stage and resources. Many people cope well, adapt and find ways to maintain their wellbeing in the face of adversity. [33] However others find it hard to adjust, and are overwhelmed by anxiety or depression in the face of uncertainty and loss. There is limited evidence on the factors that predict how people respond, and research is needed to identify those likely to need support. Research on the factors associated with coping well is also essential and would inform the development of wellbeing resources.

The National Institute for Health and Care Excellence (2004) identifies four levels of psychological support that should be available for people with advanced cancer. This ranges from information-giving and general psychological support provided by any health and social care professional to specialist psychological interventions delivered by applied psychologists (e.g. clinical, counselling or health psychologists) and mental health specialists. We have developed this model to link each level of psychological support with groups of individuals who may have specific mental health and wellbeing needs following diagnosis of a life-limiting illness (Figure 2). The NICE (2004) guidance was published two decades ago and is focused on people with cancer. Updated and expanded guidance on psychological support for people with a life-limiting illness, irrespective of diagnosis, is needed.

> MAIN will work towards generating and sharing evidence to develop a more comprehensive understanding of the range of mental health and wellbeing support needs of people with a life-limiting illness, and how these can be addressed.

Figure 2: Mental health and wellbeing needs mapped on to NICE (2004) levels of support

People impacted by a life-limiting illness who have the resources, skills and networks they need to cope well.	**NICE Level 1 Support** • Information-giving • Compassionate communication • General psychological support	**Information giving**
People impacted by a life-limiting illness who subsequently experience significant negative effects on their mental health.	**NICE Level 2 Support** • Psychological techniques delivered by trained health and social care staff	**Low intensity support**
People impacted by an life-limiting illness who are subsequently diagnosed with a clinical mental disorder.	**NICE Level 3 Support** • Specific psychological interventions delivered by trained and supervised counsellors	**High intensity support**
People with clinically diagnosed mental disorders who subsequently are impacted by an life-limiting illness.	**NICE Level 3 or 4 Support** • Level 3 support OR specialist psychological and psychiatric intervention delivered by a mental health specialist	
People with severe mental illness (e.g. schizophrenia) who subsequently are impacted by an life-limiting physical illness.	**NICE Level 4 Support** • Specialist psychological and psychiatric intervention delivered by a mental health specialist • Integrated and coordinated palliative and mental health care	

Effectiveness of mental health and wellbeing support interventions

There is growing evidence for the feasibility and effectiveness of structured interventions to improve mental health and wellbeing for people with a life-limiting illness, their families, carers or close persons [34-38]. Several therapeutic approaches have been evaluated in palliative populations including meaning-making[35] Acceptance and Commitment Therapy (ACT),[36] Mindfulness[34], Dignity Therapy[39] Cognitive Behaviour Therapy (CBT)[40], Narrative Therapy[41], Systemic Family Therapy[42] and Psychodynamic Psychotherapy[43]. Evidence for some approaches is more developed than for others – for instance a systematic review of psychosocial interventions for people with cancer identified 20 studies relating to CBT but no evaluation of Acceptance and Commitment Therapy.[44] Overall, the evidence for the effectiveness of psychological interventions is mixed but promising. Large scale studies are now needed to evaluate the effectiveness and cost-effectiveness of these approaches, and to identify the factors that facilitate cost-effective implementation in practice.

> MAIN seeks to share evidence on the evaluation and implementation of mental health and wellbeing support interventions for people with a life-limiting illness across the UK.

Low intensity interventions for mental health and wellbeing

Low intensity interventions include guided self-help, online self-directed psychological therapy, group-based or individual support delivered by health and social care professionals or volunteers who have received training in psychological approaches (but are not counsellors or mental health specialists).

Low intensity interventions are typically brief and represent a cost-effective way of increasing access to mental health and wellbeing support. Such interventions may be suited to addressing the needs of people who experience negative impacts on their mental wellbeing following diagnosis of a life-limiting illness, but do not have a clinically diagnosed problem (See Figure 2: NICE Level 2). Stepped care ensures that the person receives the right treatment in a timely way – if a low intensity intervention is inadequate, the individual should be referred for a high intensity intervention, delivered by a mental health specialist. Research is needed to adapt existing psychological therapies so they can be delivered more widely in brief low-intensity formats, and tailored to the needs of people with life-limiting illness.

> MAIN will provide a forum for the development of research collaborations focused on designing, testing, and implementing low intensity mental wellbeing interventions so that more people can access support.

High intensity interventions for mental health and wellbeing

High intensity interventions refer to interventions delivered by applied mental health specialists, such as applied psychologists, counsellors, and psychotherapists. These are for individuals with moderate to severe mental health problems which have arisen pre or post diagnosis of a life limiting illness (See Figure 2: NICE Levels 3 and 4). These interventions are more likely to involve one-to-one support delivered over a longer period. Access to applied psychologists, clinical psychologists and other mental health specialists is limited for people referred for specialist palliative care, with just 19% of hospices having access to an in-house clinical psychologist (and most will be employed part-time). It is vital that people who need high intensity interventions can be identified and referred, so they can quickly access this support. It is also important that the right level of support is available to each person so that care can be provided in line with individual levels of need.[45]

> MAIN will provide a forum for the development and sharing of research and guidance relating to mental health needs assessment, ensuring that people at risk of moderate to severe problems have access to high intensity mental health support.

Training for health and social care professionals

All health and social care professionals involved in providing care to people with an advanced life-limiting illness should receive training in mental health and wellbeing support. This includes professionals working in the community and hospital settings and not just specialist palliative care or hospice staff. At a minimum, in line with NICE (2004) Level 1, all healthcare professionals should be able to guide people to mental health and wellbeing information and support.

Health and social care professionals who routinely care for people with a life-limiting illness (e.g. hospice or palliative care team staff) should be trained in basic psychological support skills. Such training would enable them to incorporate evidence-based psychological techniques into the care they provide, complementing and extending their current practices.

There should also be opportunities for health and social care staff to develop their skills in facilitating group-based support based on specific therapies. For example, this might include group-based Acceptance and Commitment Therapy (ACT) or Cognitive Behavioural Therapy (CBT). Such workshops would provide people impacted by life-limiting illness with additional tools and strategies to support their mental wellbeing as they navigate the psychological impact of advanced illness.

Access to expert psychologist support is limited in hospice and palliative care settings[45]. To make the most of the resources available, applied psychologists and mental health specialists have an important role to play in training and supporting health and social care professionals to provide evidence-based psychological support. Social workers with specific training in psychological approaches could also have a key role to play in delivering lower intensity psychological interventions.

Research is needed to determine how training can be delivered in terms of content, format and supervision. Staff training needs to be delivered in a flexible format (e.g. part-time, blended learning), and supervisors need to be identified.

Undergraduate and postgraduate training programmes for doctors, nurses and allied health professionals should cover mental health and wellbeing support as part of the curriculum. A significant number of hospital inpatients are in their last year of life,[46] and all newly qualified health and social care professionals need to be able to recognise this and provide support as needed.

> MAIN will promote research and knowledge exchange activities to inform the development of mental health and wellbeing training programmes and resources for health and social care professionals who encounter serious illness, dying, death and bereavement.

Spiritual care

An advanced life-limiting illness can result in loss of meaning and purpose, a sense of hopelessness and isolation. At the same time, for some people a sense of limited time can lead to a reorientation and revaluation of life, and a focus on what is most important.[47] Approaches such as meaning-making, which involves revising core beliefs or one's sense of meaning in life, can help people adjust. More research is needed to explore the role of health and social care professionals in the provision of good spiritual care to those for whom this is important, irrespective of where they receive care.

> MAIN provides a forum for research collaboration and knowledge exchange activities focused on spiritual wellbeing of people impacted by life-limiting illness.

Mental health and wellbeing support for caregivers, families and close persons

SINCE the Covid-19 pandemic, there has been a significant and sustained increase in the number of people spending their last months of life at home.[48] Caregivers have provided more palliative care than ever before. Caregivers are partners, relatives and friends who provide care that requires a significant amount of time over months to years. They perform a wide range of physically, socially, emotionally and financially demanding tasks.[49] It is estimated that there are around 500,000 caregivers of people approaching end of life across the UK. Caregivers of people with cancer provide around 70 hours of care per week during the cared-for persons last months of life.[50]

Caring for someone with a life-limiting illness is challenging. Caregivers often manage the cared-for person's personal and practical care, physical symptoms such as pain, and emotional issues such as fear and low mood, while dealing with their own feelings of loss, fear, or guilt. Caregiving is stressful, as caregivers are not trained for these tasks. It can also be isolating and physically tiring.

Mental health and wellbeing support needs to be available to caregivers and families, to maintain their own wellbeing and to help them to support the cared for person. Evidence is needed to identify which mental health and wellbeing interventions are effective and cost-effective for caregivers and families.[51, 52] Research on the role of finance, ethnicity, faith and culture in the context of carer mental health is needed. Bereavement support (including pre-bereavement/anticipatory grief support) is also integral to palliative care, though it is under-researched and not widely available[53]. It represents another key area for further research and service development.

> MAIN provides a forum for research and knowledge exchange activities that aim to progress the development and implementation of mental health and wellbeing support for caregivers, families and people close to a person with a life-limiting illness.

Staff wellbeing

Healthcare professionals have high rates of sickness absence, burnout, and distress compared to other sectors.[54] Absence rates are reported as 5.4% in England,[55] 5.7% in Scotland[56] and 6.9% in Wales.[57] Anxiety, stress, and depression are consistently the most often reported reasons for sickness absence.[55] Stress and depression has been found to directly affect intention to leave the nursing profession.[58] Poor mental health in the NHS is estimated to cost £1749-£2174 per employee per year.[59] Promoting staff wellbeing is essential in order to improve recruitment, retention and morale of staff, and secure a fit-for-purpose workforce.[60]

In addition to generic stressors, palliative care professionals experience unique stressors such as regular exposure to dying, death and bereavement, uncontrollability of symptoms, patient complexity, and family reactions to loss or anticipating loss.[61] Staff caring for people with a life-limiting illness in the community can feel lonely and isolated.[62] High-quality evidence on interventions that improve mental wellbeing amongst staff caring for people with a life limiting illness is needed to guide the development of effective resources and interventions.

> MAIN provides a forum for research collaboration and knowledge exchange aiming to increase the availability of mental health and wellbeing support for all staff who care for people impacted by a life limiting illness.

Harnessing digital interventions to increase access to support

Digital technology can play an important role in increasing access to cost-effective support for people with a life-limiting illness. There is good evidence for the acceptability and value of online support, with digital interventions being used for education, symptom management, and information-sharing.[63]

The pandemic has accelerated the use of digital technology, resulting in a growing interest in hybrid, novel, synchronous and asynchronous online psychosocial interventions.[64] Digital interventions can widen access to mental health and wellbeing support by enabling people in remote and rural areas, or those who have limited mobility to access services. However, there is also the potential to widen inequalities, with some people less able to utilise digital technology due to availability, cost, lack of confidence or knowledge and physical impairment. Research is needed to guide the development of digital and online support for mental health and wellbeing, in ways that enhance access and minimise the risk of widening inequalities.

> MAIN promotes research collaborations and knowledge exchange activities that harness digital technology to increase access to mental health and wellbeing support for people impacted by life-limiting illness.

What will MAIN do?

The Mental health and wellbeing in Advanced Illness Network (MAIN) provides a forum to progress research and knowledge exchange in relation to mental health and wellbeing for people impacted by life-limiting illness.

The network will:

- Provide opportunities for sharing new research and promoting knowledge exchange.
- Identify and prioritise key areas for future mental health and wellbeing research.
- Support the development of research collaborations and funding applications.
- Ensure that people impacted by an advanced life-limiting illness have a say in what is needed.
- Work with stakeholder organisations to identify policy levers for better mental health and wellbeing support for people impacted by life-limiting illness.

We plan to:

- Set up a network website where we will share information about key events and activities.

- Run a series of research and knowledge exchange webinars, each focused on a key issue relating to mental health and wellbeing.
- Run a research question prioritisation exercise to identify and prioritise key questions for future research.
- Support early career researchers interested in this area and hold in-person networking events to bring together people from all settings (e.g. academic, clinical, policy) to collaborate on, and advance, research proposals.
- Ensure that people who have life limiting illness, or who have cared for someone with a life-limiting illness are involved in all aspects of our work.
- Evaluate our progress, and seek funding to sustain and further develop the network over time.

Our activities will enable us to accelerate progress towards ensuring that everyone in the UK impacted by a life-limiting illness can access appropriate evidence-based mental health and wellbeing support when they need it.

Joining MAIN

The network is open to anyone interested in mental health and wellbeing in advanced illness. You can sign up for information on network events here.

Or you can follow us on X:

✖ @theMAINevent24

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